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THE UNIVERSITY OF ALBERTA

ALZHEIMER'S DISEASE AND PSYCHIATRIC INSTITUTIONALIZATION: EXPERIENCES OF FAMILY CAREGIVERS

BY

(C)

JAYNE ELIZABETH WILLOUGHBY

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE
OF MASTER OF SCIENCE
IN
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FACULTY OF HOME ECONOMICS

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SPRING, 1988

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **ALZHEIMER'S DISEASE AND PSYCHIATRIC INSTITUTIONALIZATION: EXPERIENCES OF FAMILY CAREGIVERS** submitted by **JAYNE ELIZABETH WILLOUGHBY** in partial fulfillment of the requirements for the degree of **MASTER OF SCIENCE in FAMILY STUDIES.**

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ABSTRACT

Although family caregivers of relatives suffering from Alzheimer's disease are receiving increased attention in the research literature and public media, little attention has been given to family caregivers' experiences with a relative suffering from Alzheimer's disease, who reside in a psychiatric institution. Psychiatric institutionalization is currently one alternative to management of the aggressive and wandering behaviors of those suffering from the disease.

A qualitative method was utilized to examine the phenomenon of family caregiving of a relative suffering from Alzheimer's disease, who resided in a psychiatric institution. The sample consisted of ten family caregivers whose relative resided in the psychiatric institution. Open-ended interviews were tape recorded and transcribed verbatim. Through continual comparative analysis, data were categorized into commonly occurring themes. Emergent concepts and hypotheses were verified through additional interviews.

Caregiving was found to be a five stage process which took place over a number of years. Family caregivers experienced changes in thought and changes in interaction with others. These changes became the properties associated with the five stages in the process of caregiving.

Data illustrate patterns of family caregiver loss of control of care management, increased interaction with formal caregivers, and increased social isolation of primary family caregivers.

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I. INTRODUCTION

As the percentage of elderly people in the population increases, more attention is being given to issues which are particularly troublesome for this group. Dementias are not uncommon among the elderly, and in the past two decades increasing interest has been given to a form of dementia called Alzheimer's disease.

Alzheimer's disease is a degenerative disorder which affects cells of the brain, and was first identified by a physician named Alois Alzheimer in 1906 (Mulder, 1980). The onset of the disease is gradual and it usually affects individuals over 65 years of age, though it has occurred as early as 40 (Bartol, 1979; Gwyther & Matteson, 1983). The duration of the disease is usually from 5 to 10 years and leads to death (Gwyther & Matteson, 1983). The neuronal changes in the brain are characterized by neurofibrillary tangles, senile plaque formation, ventricular enlargement, severe atrophy of the brain cortex and degeneration of the nerve cells (Gwyther & Matteson, 1983; Hayter, 1974; Schneider & Emer, 1985; Williams, 1986). These changes are manifested by memory loss, impaired judgement, inability to engage in abstract thought, mood changes, personality changes, and behavior changes (Gwyther & Matteson, 1983). There is considerable variability in the progression of the disease, but the average time from diagnosis to death has been estimated at seven years (Ninos & Makohon, 1985). The disease usually progresses from memory loss, time disorientation and lack of spontaneity, to increased memory loss, verbal communication difficulties, perseveration, and wandering. It then progresses to include motor skill abnormalities, disinterest in food, severe memory loss, and severe communication difficulties (Hayter, 1974). Several authors have discussed the progression of the disease in terms of specific stages (Bartko et al., 1983; Burnside, 1979; Charles et al., 1982; Hayter, 1974; Williams, 1986), but this concept has not been universally accepted (Zarit & Zarit, 1982). Individuals who suffer from Alzheimer's disease are usually otherwise physically healthy (Hayter, 1974). Researchers are currently investigating relationships between Alzheimer's disease and slow viruses, autoimmune processes, genetic factors and aluminum toxicity (Bartko et al., 1983; Nee, 1985; Schmidt, 1983), but there is presently no known cause of the disease (Bartko et al., 1983; Burnside, 1979; Charles et al., 1982; Hayter, 1974; Zarit & Zarit, 1982).

Physicians are frequently reluctant to give a diagnosis of Alzheimer's disease, because conclusive diagnosis is possible only after a positive brain biopsy, which is rarely done prior to death (Dahl, 1983). Many physicians prefer to label the symptoms more generally as senile dementia or as senile dementia of the Alzheimer's type, though the physicians guide to diagnostic criteria for mental disorders indicates that nearly all cases of senile and presenile dementia are associated with Alzheimer's disease (Spitzer, 1980).

An estimated 1.5 million individuals (Gwyther & Matteson, 1983), or between five (Gwyther & Matteson, 1983) and ten (Luke, 1982) percent of the population over the age of 65, are afflicted with Alzheimer's disease in the United States. In Canada it has been estimated that 10,000 deaths per year are attributed to Alzheimer's disease and that as many as 100,000 to 300,000 individuals may be afflicted with the disease in varying degrees at a given time (Health and Welfare Canada, 1984).

A large amount of the available literature about Alzheimer's disease focuses on management of the diseased individual (Bartko et al., 1983; Bartol, 1979; Berkman & Rehr, 1975; Burnside, 1979; Charles et al., 1982; Chisholm et al., 1982; Cohen et al., 1984; Cutler & Narang, 1985; Dahl, 1983; Gobolt, 1986; Hamsher, 1983; Hayter, 1974;

LaPorte, 1982; Ninos & Makohon, 1985; Schafer, 1985; Shomaker, 1986; Thornton et al., 1986; Williams, 1986), though concerns about support for family members of individuals who suffer from Alzheimer's disease have been expressed by health care workers both in the literature and in practical settings.

A review of the literature unveiled several assumptions and untouched areas of examination relating to family members and their relatives who are afflicated with Alzheimer's disease. It was found that family members were not generally acknowledged as caregivers after their relative was institutionalized in any type of health care facility. There was little consideration given to family members' experiences and feelings after the relative was institutionalized, and there was little discussion about those family members who did not attend formal support groups.

No statistics were available which reflected where individuals who suffered from Alzheimer's disease were cared for during the progression of the disease, but several authors reported that most elderly demented individuals are cared for in the community and that the most frequent community caregivers are family members (Barnes et al., 1981; Horowitz, 1985; Poulshock & Deimling, 1984; Rabins et al., 1982; Reifler & Wu, 1982; Robertson & Reisner, 1982; Zarit et al., 1980). However, individuals suffering from Alzheimer's disease were usually institutionalized in the later stages of the disease, when the family could no longer cope with the care and supervision which was required (Hayter, 1974; Willisma, 1986; Zarit et al., 1985). The major manifestation of Alzheimer's disease is mental impairment. Johnson and Johnson (1983) contend that a family caregiver's inability to cope with the care and supervision of the relative is influenced more often by mental impairment than by physical impairment of the elderly care recipient.

Individuals who suffer from the disease are frequently admitted to health care institutions for treatment at varying times during the progression of the disease. Alzheimer's disease is considered a chronic treatment situation by health care professionals, and the acute care facility is not perceived as the appropriate place for long-term treatment of the individual suffering from Alzheimer's disease. Difficulties in care management are increased when behavioral manifestations of individuals with Alzheimer's disease create difficulties within nursing home and hospital environments. These facilities are frequently not equipped to handle the needs of individuals suffering from Alzheimer's disease, particularly in the later stages (Aronson & Lipkowitz, 1981; Bartko et al., 1983). Most nursing homes and general hospitals in Canada are not legally designated or designed to confine individuals within facility boundaries, nor are they equipped or prepared to manage severe aggressive behaviors of their residents. The disturbing behaviors of individuals suffering from Alzheimer's disease, such as continual aggressive acts and wandering, have created management difficulties for family caregivers and health care personnel. The difficulties presented by care recipients have frequently resulted in psychiatric institutionalization of that individual. Psychiatric institutions are legally designated for confinement of individuals without their consent in situations where that individual is perceived as a danger to himself and/or others by health care authorities.

Treatment of any individual in a psychiatric institution is stressful, and the experience raises many issues for family members (Rose, 1983). Stigmas attached to 'mental illness' can bring about fears that lead to a denial of the need for psychiatric treatment (Horwitz, 1978). Family members may become ashamed or embarrassed about the individual who is identified as having a mental illness.

There is frequently an element of contagion to beliefs about mental illness. Spread of the stigma to include family members may be feared, feelings which may be reinforced through perceived rejection or blame by others (Anderson & Meissel, 1976; Goffman, 1963). Fears could also be supported by beliefs that mental illness is genetically transferred or passed on through physical contact. For those reasons, hospitalization for treatment of a mental illness is viewed by family members as a 'private matter' and as a 'last resort' (Rose, 1983). Family members must also deal with their assumptions and perceptions about psychiatric institutions which were found to be based on previous experience with health care institutions (Rose, 1983). It is assumed that the psychiatric institutionalization of an individual suffering from Alzheimer's disease has an impact on family caregivers. This impact may be similar to that which is experienced by family members of individuals institutionalized for treatment of other diagnosed mental illnesses.

Family caregivers who have a relative suffering from Alzheimer's disease and who is residing in a psychiatric institution must deal with the traumas related to the 'ongoing funeral' of Alzheimer's disease (Gwyther & Matteson, 1983). They must also contend with the stress of their relative's admission to a psychiatric institution for treatment of the disease.

Statement of the Purpose

Though psychiatric institutionalization has been one management strategy for some individuals who suffer from Alzheimer's disease, there has been no reported examination of family caregiver experience with these individuals. Family caregivers' experiences with relatives suffering from Alzheimer's disease and who are admitted to a psychiatric institution are salient to government groups and policy makers as the elderly population increases and facilities and services are proposed. The purpose of this study was to examine family caregivers' experiences with a relative who suffered from Alzheimer's disease and who resided in a psychiatric institution.

Definition of Terms

Family

The term 'family' in this study refers to that social group which was defined as family by the individuals who participated in the study. The term 'relative' was used to identify individuals who were identified by the subject as being a member of the family. The relative who suffered from Alzheimer's disease will be referred to as the ADR--Alzheimer's Diseased Relative--during this discussion.

Family Caregiver

'Caregiver' has been defined by Hirst and Metcalf (1986) as "one who attempts to meet the physiological and psychological needs of the individual" (p. 24). They indicate that this definition refers to both family members and health care workers. 'Family caregiver' refers to identified family members who provided any amount of care to the ailing individual in the form of physical or psychological support. A primary family caregiver was that family member identified by participants as holding the majority of responsibility for physical and/or psychological care for the relative suffering from Alzheimer's disease. This definition of a primary family caregiver corresponds to the definition used by Zarit et al. (1980), where primary family caregivers were "principally responsible for providing or coordinating the resources required by the person with dementia" (p. 650).

Psychiatric Institution

A psychiatric institution houses individuals who are receiving treatment for a variety of psychiatric disorders. The institution differs from other health care facilities in that it is legally designed to treat and/or confine individuals without their consent for varying periods of time. Two such institutions exist in the province of Alberta.

II. SURVEY OF THE LITERATURE

Literature was reviewed which addressed issues related to Alzheimer's disease and family caregiving and to the impact that psychiatric institutionalization has on family members. Several issues which were assumed to be salient to this group of family caregivers were not addressed in the literature. There was little investigation of interactions among relatives of individuals suffering from Alzheimer's disease or between family members and informal and formal supporters. There was minimal discussion of family members' feelings when a relative was institutionalized in a health care facility. Family members who did not attend formal support groups were not considered by researchers in their evaluations of support programmes. There was also no discussion of issues which were of concern to family caregivers who placed their relative suffering from Alzheimer's disease in a psychiatric institution. Some of the underlying assumptions reflected in the literature were:

1. Family members want to care for their ailing elderly relatives despite the burdens and difficulties encountered.
2. In families where there is a relative suffering from Alzheimer's disease outside an institution, there is only one major caregiver.
3. The decision to institutionalize an elderly family member is made by family members.
4. A family member is no longer perceived as a caregiver once the relative with Alzheimer's disease is institutionalized.
5. Formal support groups are beneficial for family members who have a relative suffering from Alzheimer's disease.
6. Psychiatric institutionalization is stressful for family members.

These assumptions provide the structure for the following discussion of the literature:

Assumption 1: Responsibility to Care

Several authors stressed that family abandonment of the elderly is a myth and that institutionalization of an elderly family member is usually perceived by family members as a last resort (Aronson & Lipkowitz, 1981; Dietsche & Pollman, 1982; Greene, 1982; Hawranik, 1985; Hayter, 1982; Helphand & Porter, 1981; Hirst & Metcalf, 1986; Lebowitz, 1978, 1985; Lynott, 1983; Mace, 1984; Moss & Kurland, 1979; Reifler & Wu, 1982; Treas, 1977; York & Calsyn, 1977).

Much of the literature on family caregiving suggested different methods of responding to behaviors of the individual with Alzheimer's disease. These recommended management strategies frequently involved role changes for family members. The strain experienced by family members resulting from role change was alluded to by several authors (Haytor, 1982; Kapust, 1982; Mace, 1984; MacVicar & Archbold, 1976; National Advisory Council on Aging, 1984; Power, 1979; Rabins et al., 1982).

There has been increased interest by researchers on issues related to caregiver burden and coping abilities of the primary family caregivers in these families (George & Gwyther, 1986; Gilhooly, 1984, 1986; Kraus, 1984; Pratt et al., 1985; Zarit & Zarit, 1982; Zarit et al., 1980, 1985, 1986). The focus in the research has been on the identification of indicators of burden, the measurement of burden and the impact of subjective caregiving burden on decision-making regarding institutionalization. Most authors proposed practical measures for family and formal caregivers to decrease family caregiver burden. Institutionalization of a family member suffering from Alzheimer's disease occurred when the burdens of caregiving became too great for the family members (Zarit et al., 1980) and most often occurred when the health of the family caregiver deteriorated (Montgomery, 1984; Rakowski & Clark, 1985). Gilhooly (1984) found that though many of her subjects reported "experiencing considerable burden," their mental health ratings were not consistent with the assumption that caregiving had a negative impact on the well-being of the family caregivers.

This type of inconsistency in the findings of caregiver burden research is not uncommon. Scholars indicated that family members do wish to care for their ailing elderly at home, despite the reported burdens experienced. Little research has unveiled the dynamics of family relationships in these situations.

Assumption 2: Major Family Caregiver

One of the most frequently addressed issues in the literature about Alzheimer's disease was that of family caregiving. However, those who discussed family caregivers did not study the whole family nor the interactions among family members. They focused on the perceptions and experiences of one family member who was primarily responsible for caregiving and/or care management. This reinforced the assumption that in families where there is a relative suffering from Alzheimer's disease who is being cared for at home, there is only one major caregiver.

Feelings and perceptions of primary family caregivers were extensively reported in the literature. Some of those cited were: anger at the situation, the patient, and/or other family members, depression, grief, isolation, fear, frustration, burden, anxiety, guilt and fatigue (Barnes et al., 1981; Breu & Dracup, 1978; Cohen, 1984; Glosser & Wexler, 1985; Gwyther & Matteson, 1983; Hampe, 1975; Kapust, 1982; Kart, 1981; Labarger, 1981; Lezak, 1978; Mace, 1984; Mailick, 1979; Poulshock & Deimling, 1984; Rabins et al., 1982; Reifler & Wu, 1982; Robertson & Reisner, 1982; Scott et al., 1986; Tusink & Mahler, 1984; Thompson & Doll, 1982; Zarit et al., 1980).

Family conflicts were also reported as being a part of the family caregiving experience (Gwyther & Matteson, 1983; Kart, 1981; Lezak, 1978; Rabins et al., 1982). These caregiver perceptions and feelings were frequently reported, without explanation of how the information was gathered.

The research about family caregiving which was reviewed did not include more than one family caregiver. The family member who was used to gather data about caregiving was the primary family caregiver. Reported feelings of primary family caregivers reinforced the notion of a single family caregiver in this type of situation. Reports of family conflict indicated that primary family caregivers were not totally isolated from other family members. Use of the primary family caregiver as the only family participant in studies examining family caregiving issues does not allow the researcher to examine the complexity of the phenomenon or the perceptions of other family members who may be involved to lesser degrees in the caregiving.

Assumption 3: Decision-Making and Institutionalization

Scholars who discussed the family decision-making process did not include examination of the role of formal caregivers. This suggested that researchers assumed family members were solely responsible for the decision to institutionalize their elderly relative. The argument was that institutionalization of a family member suffering from Alzheimer's disease occurred when the burden of caregiving became too great for the family caregivers (Zarit et al., 1980). This often occurred when the caregiver's own health deteriorated (Montgomery, 1984; Rakowski & Clark, 1985), or if the mental health of the care recipient was poor (Johnson & Johnson, 1983). The specific rationale behind institutionalization varies with each situation, but most researchers would agree that the decision to institutionalize a relative occurs when family members perceive their situation to be 'intolerable' (Aronson & Lipkowtiz, 1981; Johnson & Johnson, 1983; Johnson & Werner, 1982; Lynott, 1983; Zarit et al., 1980).

The process of decision-making regarding institutionalization was identified as a strain for family caregivers of an elderly family member. During the decision-making process, family members often found themselves in conflict with each other (Johnson & Johnson, 1983; National Council on Aging, 1984). Family conflicts usually resulted from different perceptions of the situation and perceived filial obligations (Greene, 1982; Johnson & Johnson, 1983; Johnson & Werner, 1982; Lebowitz, 1978; Lynott, 1983) or lack of planning and discussion regarding placement prior to the institutionalization (Greene, 1982).

Researchers who addressed decision-making issues related to institutionalization of an elderly family member did not include reports from or about the involvement of formal caregivers in the decision-making process. Only reports from primary family caregivers were considered. Because of this omission, the assumption that the decision regarding institutionalization of the elderly is made entirely by family members was reinforced.

Assumption 4: Caregiving After Institutionalization

If a caregiver is one who attempts to meet the physiological and psychological needs (Hirst & Metcalf, 1986) then whether the recipient of care is institutionalized should not necessarily preclude caregiving by a family member. However, most of the literature about family caregiving of individuals with Alzheimer's disease focused on family members who were caregiving while the relative resided outside an institution. Some researchers have found that family members continued to be involved with the ailing family member after he was institutionalized (Smets, 1982; Wiancko et al., 1986; York & Caslyn, 1977). Though most of the research on caregiver burden concentrated on primary caregivers' experiences while the ailing relative was being cared for at home, Pratt et al. (1985) indicated that caregiver burden did not subside as expected after the care recipient was institutionalized. Wiancko et al. (1986) stated that with institutionalization of a cognitively impaired spouse, the dynamics of the burden changed for family caregivers.

After a relative is institutionalized, family members must learn new roles and develop new skills to deal with health care professionals (Hayter, 1982; Hirst & Metcalf, 1986; Mace, 1984; Rakowski & Clark, 1985; Safford, 1980; Wiancko et al., 1986; York & Calsyn, 1977). Barnes et al. (1981) report that these new roles were often adopted by family members with reluctance and feelings of inadequacy.

Examination of literature where scholars examined family caregivers from a formal caregiving perspective unveiled the findings that 'family interference' was the result of role changes for family members, lack of information, lack of involvement and responsibility for care of the sick relative, and discrepancy in expectations of formal and family caregivers (Robinson & Thorne, 1984). Interfering behaviors included: demanding undue attention, criticism of care, complaints about conditions, sabotage of patients' compliance, and generally making a nuisance of themselves. The authors suggest that formal caregivers have been socialized to resist these behaviors. Smets (1982) proposed that family members behave in ways that are expected of them by health professionals. If health professionals hold negative attitudes toward families, it creates conflict between family members and the health care workers who provide formalized support.

Researchers have focused on family members as caregivers prior to institutionalization of the care recipient, though some have reported that family members remained involved with their relative after institutionalization. Several authors mentioned the role changes and adjustments required by family caregivers after institutionalization of the care recipient, but research addressing this issue is minimal. The concentration of attention to family caregivers prior to institutionalization, combined with the health care literature examining formal caregivers' negative attitudes toward family members, reinforced the assumption that family members are no longer considered as caregivers after the institutionalization of the care recipient.

Assumption 5: Formal Support Groups

Cohen and Syme (1985) defined social support as "the resources (potentially useful information or things) provided by other persons" (p. 4). A person feels supported when he feels cared for, valued, and is a member of a social network (Cobb, 1976). Social support for family caregivers can be either formal or informal (Zarit et al., 1985). Informal support is that which is provided by friends, relatives and acquaintances, and formal support is that which is provided by professional helpers (Cohen & Syme, 1985). Hayter (1982) stated that family caregivers do not get the support they need from health care professionals, partially due to the formal caregiving focus on the ailing individual. She asserted that relatives need help in understanding the disease and treatments, they need to be allowed to ventilate their feelings, and they need reassurance and encouragement to make appropriate decisions.

Examination of the literature related to support issues in general showed that support was one of the most basic activities of nurses (Grossman-Schulz & Feeley, 1984; Schoenhofer, 1984). Again, support was largely discussed in terms of the individual patient.

Grossman-Schulz and Feeley (1984) found that the definition of support provided by nurses varied. Nurses were unclear about what criteria were used to evaluate supportive measures. Hawranik (1985) suggested that formalized family support was not adequately assessed after families had been 'plugged in' to the system. She cautioned that satisfaction of the support received by family members may be either felt satisfaction, or it may be an acceptance of the situation based on family members' perceptions that no other alternatives are available to them.

Support groups for the families of the institutionalized individual suffering from Alzheimer's disease are usually initiated by health care professionals. This also appeared to be true of family support groups of non-institutionalized individuals suffering from the disease. The groups frequently have an educational component to them, and they provide an opportunity for family members to share their feelings and experiences with other group members. Aronson and Yatzkan (1984) describe the support group movement for the family members of individuals suffering from Alzheimer's disease as a "'seat of the pants' movement that has sprung up to fill the large gaps in service that exist" (p. 5).

Reports of evaluation of existing support groups are limited. Glosser and Wexler (1985) found that the family members' evaluations of an educational/support group were generally positive, despite limitations of the evaluation tool used. Studies of support groups done by Lazarus et al. (1981) and La Vorgna (1979) found that the number of invited participants who chose not to attend group sessions were 3 (37.5% of the total invited participants) and 5 (33.3% of the total invited participants), respectively. There was no discussion of other forms of social support utilized by these individuals. Evaluations from support group participants were positive. A major limitation of this research was that the findings were obtained from small sample sizes and the studies took place over a short period of time. Despite the absence of substantial evaluative research regarding the usefulness of support groups, the underlying assumption remains in the literature that these groups are a helpful method of providing support for family members who have a relative suffering from Alzheimer's disease.

Assumption 6: Families and Psychiatric Institutionalization

Because the phenomenon being studied concerned admission of a family member to a psychiatric institution for treatment of Alzheimer's disease and this specific group of individuals has not been discussed in the literature, general family attitudes related to mental illness and psychiatric institutionalization were explored. Issues considered in the literature were family members' definitions of mental illness, family dynamics, the impact of psychiatric institutionalization on families, the negative social reactions to mental illness and feelings that family members have about the experience (Anderson & Meisel, 1976; Goffman, 1963; Horwitz, 1978; Rose, 1983; Vannicelli et al., 1980).

Few researchers have examined family members' attitudes about mental illness (Vannicelli et al., 1980). However, Anderson and Meisel (1976) pointed out that "families cope least well with situations or behaviors that threaten their sense of security" (p. 869) and that psychiatric institutionalization of a family member has been found to be one such situation. The authors discussed how mental illness of a family member brings about isolation of that family from the community. Feelings of shame or embarrassment may result in expectations from family members that others will reject them, stigmatize them, or blame them for their part in promoting the mental illness.

Rose (1983) found that the concerns which family members experienced when a relative was institutionalized for treatment of a psychiatric disorder reflected their own definitions of mental illness. They attempted to mold their definitions of mental illness so that they were acceptable to them and could be applied to their relative. Vannicelli et al. (1980) found that social class, ethnic background, and peer group influences had more impact on the development of attitudes about mental illness than did the subjects' own experiences with mental illness. Thus, it appeared that an individual's definition of mental illness is largely influenced by interactions and relationships with others in the community.

The perceived social stigma associated with admission to a psychiatric institution determined which individuals family members contacted for help or support (Rose, 1983). Family members "became protective of the patient and they came to view mental illness as a 'private' experience" (Rose, 1983, p. 509). Available supports were perceived as being limited, which in turn, influenced family members' understanding of the illness.

Family members also had to deal with preconceptions about psychiatric hospitals as being 'asylums' (Rose, 1983). Assessments of the psychiatric institution were tied to definitions of mental illness. Family members frequently looked for similarities between their experiences with the psychiatric institution and past experiences with other health care institutions.

Scholars agreed that social stigma is connected with psychiatric institutionalization. This stigma appeared to influence the experiences of family caregivers by challenging their attitudes and beliefs. Such a challenge during a period of crisis affected levels of stress experienced by family caregivers. No evidence was given to suggest whether or not family caregivers of individuals suffering from

Alzheimer's disease who were admitted to a psychiatric institution experienced similar stresses.

In summary, much of the literature indicated that the abandonment of elderly family members is a myth. Several authors discussed family caregiver issues in relation to Alzheimer's disease. These reports tended to focus on the feelings, perceptions and role changes of one primary caregiver, with limited discussion of other family members. There was some exploration of family decision-making processes related to institutionalization of an ailing family member. The assumptions apparent in this literature were that family members wanted to, and did care for their ailing relatives, despite enormous financial, physical and emotional burdens. Family caregivers were dicision-makers when institutionalization of the care recipient was considered.

The literature on formal support for family members focused on family support groups of institutionalized and non-institutionalized individuals with Alzheimer's disease. Minimal evaluation of formal support services has been reported, though the belief that formal family support groups were beneficial for family members prevailed. Recent nursing literature addressed some issues of support, but definitions of support were unclear. It was also found that some health care professionals held negative attitudes toward family caregivers, institutionalized care recipients, and that family members were no longer perceived as caregivers after the relative had been institutionalized.

Family members who experienced admission of their relative to a psychiatric institution for treatment of a mental illness experienced internal upheavals in terms of their definition of mental illness and their perceptions of psychiatric institutions. It appeared that psychiatric institutionalization of individuals suffering from Alzheimer's disease was not addressed in the literature. Thus, no assumptions were evident relating specifically to the issue of psychiatric institutionalization of a relative suffering from Alzheimer's disease.

The researcher examined experiences of family members of a relative with Alzheimer's disease who resided in a psychiatric institution. An understanding of family caregivers' experiences is basic to the identification of salient factors for these families before appropriate formal support can be provided for family members. Health professionals will not begin to be able to effectively support family members of institutionalized and non-institutionalized individuals suffering from Alzheimer's disease until family caregivers' perceptions have been systematically analyzed. Because the research into this area has been limited and the available literature reflected several assumptions, a qualitative approach was chosen to examine the phenomenon.

III. METHODOLOGY

Grounded Theory

Qualitative research generally takes an inductive approach where data are gathered in order to identify salient concepts and variables related to a phenomenon. Research which uses an inductive approach does not organize data to fit a pre-chosen theoretical framework. Rather, theory is developed from collected data. Grounded theory is one type of qualitative methodology. Theories which are discovered using a grounded theory approach are grounded in evidence found within the data.

The purpose of grounded theory is to generate theory which will "account for much of the relevant behavior" through comparative analysis of social units of any size (Glaser & Strauss, 1967, p. 30). Through the comparative process, conceptual categories are generated from evidence within the data. Conceptual categories were defined as abstractions of the evidence (Glaser & Strauss, 1967). Conceptual categories are general in nature, while the properties of the categories are more specific in nature. Glaser and Strauss (1967) stated that evidence related to a conceptual category may change or vary with each case, but that the concepts themselves will not change if the conceptual category is theoretically sound.

During initial data collection and analysis, the researcher identifies a core category which "sums up in a pattern of behavior the substance of what is going on in the data" (Glaser, 1978, p. 94). The core category is the main theme or the "main concern or problem for the people in the setting" (Glaser, 1978, p. 94). Glaser (1978) defines a basic social process (BSP) as one type of core category which has "two or more emergent stages" and "gives the feeling of process, changes, and movement over time" (p. 97). The BSP is further differentiated into the basic social psychological process (BSPP) and the basic social structural process (BSSP), which is the social structure in which the social psychological process occurs. In the phenomenon in question the basic social psychological process was caregiving and the basic social structural process was family life development. Thus, the core category in this study was the basic social process of family caregiving. In this situation, the psychological process of caregiving influenced the structural process of family life development.

Other broad or general subcategories or concepts related to the core category are also identified during initial data collection and analysis. Using a grounded theory approach, these identified concepts are then verified through further data collection and analysis. This process of verification continues until a conceptual category is considered saturated. Saturation occurs when no additional data are being found which refine the properties of a conceptual category. As similar evidence is repeatedly unveiled "the researcher becomes empirically confident that a category is saturated" (Glaser & Strauss, 1967, p. 61). Thus, grounded theory includes both inductive and deductive thinking in its process (Field & Morse, 1985).

Through continued comparison of cases, hypotheses about relationships between the concepts emerge. As the hypotheses develop, they, too, are verified through further data collection and analysis. The accumulated interrelations of concepts "form an integrated central theoretical framework--the core of the emerging theory" (Glaser & Strauss, 1967, p. 40).

During the process of theory development, the researcher turns to existing literature which provides more data to be considered during the process of abstracting concepts. Ongoing review of the literature also generates ideas about concepts and their relationships which may affect the direction of theorizing (Glaser, 1978). "Data collection continues until ... no new data and no new additions are added to the category and one overriding, or core category can explain the relationship between all of the others" (Chenitz & Swanson, 1986, p. 8).

Validity and reliability are key issues in quantitative research methodology where the approach is deductive. There is considerable debate in the scientific literature about the relationship of reliability and validity to qualitative research. Reliability refers to the ability of a study to be replicated by other researchers. Analysis in grounded theory is dependent on the "researcher's skill, creativity, time, resources, and analytic ability" (Chentitz & Swanson, 1986, p. 13). Therefore, an exact replication of a study using the grounded theory approach is not possible because no two researchers will be exactly alike. Chenitz and Swanson (1986) felt the question of whether the discovered 'grounded' theory could be applied to other similar situations over time was of greater concern when addressing issues of reliability. Leininger (1985) supported this view of reliability, stating that the phenomenon under study should "consistently reveal meaningful and accurate truths about particular phenomena" (p. 69).

One method of increasing the reliability of a theory is to test hypotheses as they develop by asking participants to evaluate the findings (Stern, 1985). This makes the findings reliable for the specific group being studied. Peer evaluation and continued literature review could also serve to increase the reliability of a qualitative study (Field & Morse, 1985).

"In quantitative research, validity refers to the degree to which an instrument measures what it is supposed to be measuring" (Polit & Hungler, 1978, p. 434). In qualitative research, validity refers to confirmation of "the truth or understandings associated with phenomena" (Leininger, 1985, p. 68). It focuses on the question of whether the theory is relevant to the particular group being studied.

Validity can be increased through the use of participant observation as a method of verifying observations made during unstructured interviews. This assures that findings obtained from questioning during the interviews with that subject are checked through observations in the natural setting. Ongoing literature review during the process of data analysis and theory development also helps to verify, elaborate, or point out factors which are not evident in the hypotheses as they are being formulated (Chenitz & Swanson, 1986). Detailed field notes about relationships between the subjects and researcher also allows the researcher to address some of the potential threats to validity.

In grounded theory, the issue of external validity is addressed through the process of theoretical sampling where the goal during subject selection and data analysis is to find a case that does not fit into the existing categories (Glaser, 1978). Negative cases foster emergence of new concepts and verification of existing categories (Glaser & Strauss, 1967). The purpose of qualitative research is not to generalize to larger or different populations, but to study the phenomenon by examining a specific sample which is directly affected by the phenomenon. The discovered theory could then be tested further by examining larger samples which are affected by the phenomenon.

Sample Selection

Theoretical or purposive sampling was the major method of sampling instituted in this study. It has been described by Glaser (1978) as a method of sampling which depends on the process of data collection and its analysis in order to promote the emergence of theory. Initially, telephone contact was made by the principle researcher with the listed next-of-kin of Alzheimer's patients who were admitted to an active, 30-bed, psychogeriatric unit at a psychiatric institution in Alberta. The names and telephone numbers of the patient's next-of-kin were obtained from the hospital records by a member of a Family Support Research Committee at the psychiatric institution. This information was obtained for all new admissions between July 18, 1986, and June 12, 1987, who were officially diagnosed with Alzheimer's disease or senile dementia of the Alzheimer's type. This was the predominant mode of entry into the families of the individuals residing in the psychiatric institution. Two additional subjects who were known by the researcher to have had experience with Alzheimer's disease were purposefully chosen to participate in the study for additional verification of the developing hypotheses. Family caregivers included individuals who were identified in the hospital record as the next-of-kin, or by the listed next-of-kin as a family member who had attempted at some point "to meet the physiological and psychological needs of the individual" suffering from the disease (Hirst & Metcalf, 1986, p. 24). Occasionally, the listed next-of-kin would identify an alternate family member who was equally or more involved in caregiving.

To determine the complexity of family caregivers' experiences, it was appropriate in some instances to interview more than one family member. Identification and selection of second, or subsequent subjects from each family depended on demographic data obtained during initial interviews with the listed next-of-kin.

A diagram of the subject's family tree was constructed during the initial interviews as a way of initiating the interview process and of identifying further potential subjects within the family. The criteria used by the investigator for selection of additional informants was cooperation of the listed next-of-kin in providing required information about the potential subject, the second family member's proximity to the city of Edmonton, and that family member's willingness to participate in the study. The exact number of family members interviewed depended on situational factors such as the number of family members of the Alzheimer's patient, the availability of family members for interviews, the level of interest and cooperation of family members, the ease at which family members were able to express themselves, the extent to which they were willing to share their experience, and the researcher's time requirement for clarification of developing hypotheses.

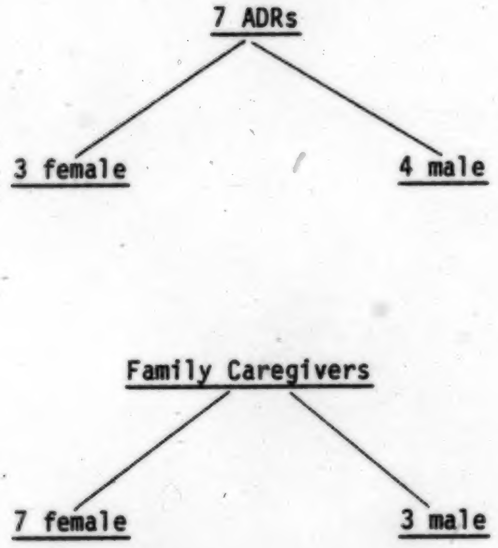
Open-ended interviews were conducted with each informant to elicit an understanding of each individual's experience. Family members were interviewed separately unless they requested otherwise, and the primary investigator explained to each informant how confidentiality was to be maintained.

The Sample

A definitive sample size was determined by the richness of the data obtained in the interviews, the number of volunteering informants, and the data analysis process (Stern, 1985). The sample consisted of nine family caregivers from six families which had a relative residing in a psychiatric institution at the time of participation in the study, plus one subject whose relative had previously resided in a psychiatric institution and had died a few years prior to participation in the study. Four relatives who had the disease were male and three were female, and their ages ranged from 66 to 84 years[1]. Three of the ten participants in the study were female spouses of ADRs who resided at the psychiatric institution. Six participants were children, three females and three males, of four relatives who suffered from Alzheimer's disease (see Figure 1). All were defined as major caregivers at some point during the progression in the diseae, though only five participants co-resided with their ADR prior to institutionalization. One female in-law of an individual suffering from the disease was included in an interview with that ailing individual's child because of the in-law's involvement in caregiving. The majority of family caregivers in this sample were female[2], and in six of seven situations the identified primary family caregiver was female.

The interviews with family caregivers were done at varying times after the ADR was admitted to the psychiatric institution. At the time of the interviews, ADRs had resided in the psychiatric institution from one to thirty-six months. Five ADRs resided on a geriatric assessment unit at the time of the family caregiver's participation in the study. One ADR resided at the institution on a long-term care unit for individuals suffering from neurological disorders at the time of the family caregiver's participation. That ailing relative had been cared for in the institution for approximately two years. One care recipient had been a resident in the psychiatric institution until his death, which occurred approximately five years prior to the family caregiver's participation in the study.

FIGURE 1: THE SAMPLE



3 spouses (PFCG)
4 adult children* (3 PFCG)

3 adult children (1 PFCG**)

(PFCG - Primary Family Caregiver)

*One daughter-in-law was included as an adult child because of her participation in caregiving. She was not a PFCG.

**In this situation there were no other family members available to assist with caregiving.

The Procedure

When a family member agreed to participate in the study, an initial meeting was arranged to obtain a formal written consent (see Appendix A) and to initiate the interview process. The purpose of the first interview with the listed next-of-kin was to obtain demographic information, to develop rapport with the informants, and to discuss the subject's experiences with the relative who suffered from the disease. Subsequent interviews were conducted with primary caregivers in the early stages of data collection and data analysis to ensure that the subject's salient experiences and perceptions were included in the data. The interviews were focused on family caregivers' experiences with the ADR and at experiences with formal caregivers. Interviews were open-ended, but an interview guide was used to provide direction during initial interviews (see Appendix B). Open-ended interviews allowed the subject to "teach" the researcher about her experiences (Stern, 1985). An elementary model of the family caregiving process emerged from the initial interviews. After this hypothesis development had begun a second interview guide was developed (see Appendix C) in which questions were directed at the rudimentary hypotheses. The final interviews were done using the second interview guide. This deductive approach to data collection promoted verification of developing hypotheses. The hypotheses were either supported or refuted by family caregivers. Data analysis of the final interviews resulted in modification of early hypotheses, yielding the five stage model of change in the family caregiving process.

There were between one and three interviews done in each family. A total of ten in-depth interviews were done and these varied in length from 2 to 6.5 hours, with an average of 2.45 hours.

The interviews were tape recorded and most interviews took place in the family members' homes. Data were collected from one subject through a telephone interview. In this case the subject was willing to share her experiences with the researcher, but was reluctant to meet face to face with the researcher. Another interview was done at the subject's work place at her request. At one point during the process of data analysis an interview was done during a subject's visit with her relative in the institution. In this case verbal consent was obtained from the subject for the researcher to accompany her to the psychiatric institution to visit her ADR. Tape recorded interviews took place prior to, and after the visit was completed. This addition of participant observation allowed the researcher to experience a visit with an individual suffering from Alzheimer's disease which increased the researcher's understanding of a family caregiver's experiences from an emic perspective.

Data Analysis

The taped interviews were transcribed verbatim as soon as possible after the termination of each interview. In the grounded theory approach to research, the phenomenon being studied is to be viewed from the perspective of the subjects. Thus, it is the subjects' "definitions, meanings, and values given to a phenomenon that are identified, described, and analyzed" (Chenitz & Swanson, 1986, p. 42). When an idea or experience emerged across successive interviews, a category was developed to encompass the theme related to those ideas or experiences. The categories which demanded subcategorization were broken down further into relating themes. Subcategorization was based on continual reemergence of themes. Through this process coding or identification of themes within the data began, and hypotheses started to develop (Stern, 1985).

It became apparent after the first few interviews that the subjects had experienced similar situations in their caregiving. This discovery led to a process of mapping data from each interview onto a time line and data from the time lines were compared. This resulted in the identification of common experiences. These common experiences eventually developed into the major categories of the discovered theory. The major categories became the stages of change in the family caregiving process. Subcategories of each of the major categories consistently recurred as the family caregiver relationships with others.

Once categories were identified, the properties about categories and concepts were then verified with informants. This ensured that there was a mutual agreement between subjects and the researcher of the salience and definition of concepts, and of the relationships between different identified concepts. Further interviews were done until the categories were considered saturated. Saturation of a category referred to the presence of enough data within a category so that it was considered theoretically complete.

Field notes containing supportive descriptive information about the interviews and the researcher's thoughts about relationships between the concepts were kept for reference during data analysis. The field notes were also a source for providing direction during subsequent interviews.

Hypothesis formation developed from the process of identification of categories and relational patterns between those categories (Stern, 1985). As the hypotheses and theories emerged, verification by the informants was sought during the taped interviews. Through this process, the developing hypotheses and theory were either proven or not proven by the informants themselves (Stern, 1985). Further literature was reviewed throughout the process of data collection and analysis, and links were made between the newly developed theory and existing literature in order to support or reject the developing theory.

In summary, there were nine stages of analysis through the use of grounded theory (Turner, 1981). These stages were: category development and category saturation, formulation of abstract definitions, use of definitions and exploitation of categories, linking categories and testing the links, connecting the findings with existing theory and the testing of emerging relationships between and within categories.

Ethical Considerations

The researcher examined family caregivers' experiences with their relative with Alzheimer's disease who resided in a psychiatric institution in Alberta. Approval of the study was given by the psychiatric institution's Research Coordination Committee on September 22, 1986 (see Appendix D). The study was also given approval by the department of Home Economics at the University of Alberta, in accordance with the university ethical requirements for research involving human subjects (see Appendix E).

The researcher did not have access to hospital records. Required information about the next-of-kin was obtained from a member of the Family Support Research Committee who was given institutional authorization to participate in this way in the research project.

Findings of the study were not released to hospital staff nor the institution's Family Support Research Committee until the data analysis was completed, and the findings approved by the primary investigator's thesis committee. Neither the tapes, nor transcribed interviews are available to the personnel of the psychiatric institution, though selected portions of the interviews have been used for illustrative purposes in the final report. Identifying information in reports of the findings has been removed or substituted to maintain informant confidentiality. This ensured anonymity of the subjects who took part in the study. The interviews were conducted individually unless the subject requested otherwise, and the confidentiality of each family member has been and will continue to be maintained.

Before the interview process began a written or verbal informed consent was obtained from each informant. In one situation where the subject was interviewed by telephone, a verbal consent was obtained by telephone and was stored on a tape separate from that of the interview.

The need for additional support for subjects was not perceived by the researcher as being necessary after their participation in the study was completed. All subjects either indicated that they were or had been receiving formal emotional support or that they knew where formal emotional support could be easily obtained and would not hesitate to seek it out should they feel the need to do so.

A short report of the research findings was forwarded to each informant upon completion of the study. Addresses were obtained from the informants when written consent for participation in the study was obtained.

The identity of the informant was not present on the tapes nor on interview transcriptions. The tapes have been completely erased and written and taped verbal consents will be stored in a locked cabinet for a period of five years. The transcribed interviews will be kept by the primary investigator for an indefinite period of time.

IV. FINDINGS

An assumption of the grounded theory approach to research "is that all groups share a specific social psychological 'problem'" (Hutchinson, 1986, p. 196). The basic social psychological problem of the phenomenon examined was family caregiving of a loved one experiencing mental deterioration as a result of Alzheimer's disease. All other categories in the model were incorporated in this single core category. As data were collected and analyzed, five stages of change in the family caregiving experience emerged. These five stages became the major subcategories of the core category of family caregiving. Examination and comparison of specific properties of each stage focused on caregiver interactions with family members and non-family. Family caregiver interactions with others reflected their shifts or changes in thought associated with each stage. Examination of properties related to interaction patterns also appeared to reflect changes in roles, positions, and relationships, though the effect which these changes had on the changes in thought were not always apparent.

Each stage signified a distinct change in thought for the family caregiver. The changes in thought, which were accompanied by changes in interaction patterns, may or may not have been accompanied by identifiable changes in behavior or activity. The stages focused on variations in thought processes which were abstracted from data spcifically related to interaction patterns. Each of the first four stages culminated in a cognitive shift which has been described by Thorne and Robinson (1987) as a new "insight" about the experience. The cognitive shift reflected a change in thinking or a change in perception of the situation. Once a cognitive shift occurred, there appeared to be a change in the nature of interactions which participants had with others. The four cognitive shifts associated with the family caregiving process were: acknowledgement that something was wrong, acknowledgement that they needed more help, acknowledgement of the decision to admit the ADR to a psychiatric institution and acknowledgement of loss. These cognitive shifts provided distinction between the stages, though an exact boundary between stages was not apparent. This suggested that there may have been some overlap between the cognitive shift of one stage and the new or revised perceptions of the next stage. During the periods of overlap the subjects likely experienced a process of verifying their new awareness before internalizing the change and moving on to deal exclusively with issues related to the subsequent stage.

Every family caregiver who was contacted by the researcher agreed to participate in the study, and all subjects expressed interest in understanding more about the experiences of family caregivers and of helping others through the sharing of their own experiences. In most situations the interview process appeared to have a cathartic effect for the subject, as minimal directive questioning was required to obtain data during the interviews.

On the two occasions where two family caregivers were interviewed together at their request, the caregiver who was initially contacted felt that the input of the additional family caregiver would be helpful in providing a clearer picture of the caregiving experience. There was little disagreement between subjects during the interviews, and the subjects frequently turned to the other family member for verification of their observations or experiences. In both cases one of the family members had a more active role in care management of the ADR, though it appeared that each of the family members had assumed specific tasks regarding care provision and care management. Analysis of the data from these two interviews was similar to the analysis of other interviews and the two subjects in each interview were considered individually rather than as one for references of frequency of responses.

During the interviews participants focused reflection of their experiences with the ADR on thoughts and feelings about activities associated with caring for the ADR. This illustrated their understanding of the basic social psychological problem of this phenomenon as family caregiving for an ADR. They were not able to identify specifically with the abstract concepts of the five stage process of family caregiving, though their reported experiences continued to 'fit' the abstracted concepts. Glaser (1978) indicated that the stages in a basic social process may or may not be apparent to the subjects and that identification of stages in a process is dependent on the stages being 'built into' the social structure associated with the basic social process.

A. Stage I: Emerging Recognition

This stage had no identifiable beginning. This is significant in that it reinforces the notion that this first stage in the process of change for family caregivers is connected in some way to that part of the life of the family caregiver which took place prior to the ADR developing Alzheimer's disease. The stage ended with the cognitive shift or new insight that something was wrong with ADR.

The length of time for this stage varied considerably among the subjects. This may have been due to factors such as the personality of the family caregiver, the availability of other trusted individuals to confer with, the caregiver's role within the family, prior knowledge of Alzheimer's disease, and the type of previous relationship the caregiver had with the ADR.

Through examination of the major theme of this stage, a process of realizing that something was wrong with the ADR was identified. Data illustrating this theme included quotations such as "I realized there was more to it," "I could see that he didn't have no [sic] sense," and "right then I knew something was amiss."

None of the family caregivers became aware during this stage that the ADR suffered from Alzheimer's disease. They all experienced some realization that "things weren't right" with the relative, which focused their attentions to the identified source of 'trouble' in the family. In other words, the ADR was identified as the individual within the family who had something wrong with him.

> And as I look back, it's just as clear as a painted picture to me now . . . I didn't deliberately say there's something wrong . . . it was more vague than that . . . . And he cornered me coming out of the [building] one time . . . and he said . . . "When is your [ADR] going to have such and such?" And I just turned . . . and said, "I wish you'd leave him alone. He's a sick man!" And when I went home I thought what a thing to say! What is he sick from? But I had the instinctive knowledge that this man was ill.

Most subjects had no prior knowledge of the disease, but many of these subjects did describe how they "vaguely" remembered reading or hearing something about the disease prior to or during this stage. They related this vague knowledge to the behaviors of the ADR in some way during this stage.

> I'd never heard the word (Alzheimer's). I had vague memories of reading the Reader's Digest article at which time I felt that whatever they said in that article was parallel to my [ADR's] behavior at the time. And I noted it, and you know, you can't go any further than that. It wasn't complete enough, or it didn't say. And I had a feeling that that must have been about Alzheimer's disease, that article. But it was a long, long time ago.

Those subjects who had prior knowledge of the disease or interactions with other individuals suffering from the disease suspected during this stage that the ADR had Alzheimer's disease. However, their suspicions were not confirmed by formal helpers until a later stage. Other subjects who had "never heard of Alzheimer's disease before" had no perceptions of what the problem was. They were only able to identify that there was something wrong with their relative.

The cognitive shift or new insight which occurred at the end of this stage was the family caregiver's acknowledgement to herself that something was wrong with the ADR.

a) Family Caregiver Interactions With Family Members

i) Relationship With The ADR. The subjects had varying amounts of contact with the ADR during this stage. Spouse caregivers had more contact with the ADR than did child caregivers. None of the participants described activities of providing physical care for the ADRs. ADRs' behaviors were described by family caregivers in terms of interactions experienced prior to the first identified unusual incident.

There seemed to be a real mental struggle while the subjects tried to make sense of what was happening in their situation.

> He was about 55 or 56 when I first became fully aware that there was something wrong. It was just like something wrong and of course you do all that outside searching. In your mind you go through all kinds of crazy things.

To make sense of the situation, subjects attempted to compare the ADRs' unusual behaviors of this stage to the behaviors and personality traits of previous years. Family caregivers frequently doubted their own observations of ADRs' behaviors and were found to personalize the behaviors of the ADR.

Interpretation of the ADR's behaviors as personal emotional attacks seemed to be most common during this stage among the spouse caregivers of ADRs, though some child caregivers expressed similar feelings either in general terms or during later stages in the process of change.

> He was trying to cope I guess, in his own way. And of course my mother was interpreting it as him really not backing her up or not trying to help her . . . and my mother would write off the fact that, you know, "Well, he's always been a little crazy. Why should he change now?" And stuff like that, you know . . . And he'd get progressively worse and she interpreted that as being kind of negative toward her rather than the ailment.
>
> You really do think you're wrong because the Alzheimer doesn't have anything else except just difficult to deal with. Now besides that they (the ADR) tell you that it's you . . . "It's not me, it's you." And if I heard that once I heard it a thousand times from my husband. "There's nothing wrong with me it's you. Mind your own business. Get out of my life." And not just a couple of times like that, but constant. And that's the reaction to the prodding to try to find out what's wrong of course . . . Verbally abusive. Very much so. Very much so. And if he had been conscious of what he was doing it would be definitely abuse.

Descriptions of communication difficulties were prevalent in the data, particularly between spouse caregivers and their ADR. However, both spouse and child caregivers talked about the strain they felt in their relationship with the ADR during this stage. There were descriptions of escalation in conflict with ADRs and feelings of emotional distance from ADRs. These episodes of conflict were frequently followed by periods of confusion and self blame by the family caregiver. Most family caregivers stated that these feelings and experiences were uncharacteristic of their relationship with the ADR.

> Well the question I asked myself many, many, many times was 'What is this?' Because I couldn't get communication from my husband to discuss any problems of any kind. No matter what came up it was like a blank wall. There were no answers coming from him . . . So I was getting no answers from him and because we had been, you know, really close and because, you know, we had such good plans for retirement, and now nothing was happening. That was the question I asked most often, 'What is this?'

ii) Relationships With Other Family Members. Some subjects reported conferring with other family members about their suspicions about the ADR's behaviors in attempts to feel assured that their observations were justified. Subjects who received affirmation of their observations experienced the cognitive shift of Stage I and moved on to Stage II. When subjects turned to other family members their perceptions were not always confirmed. Where the family caregiver's perceptions were not reinforced by others it forced the family caregiver to reassess her perceptions. This process of reassessment may have prolonged Stage I in the process for those family caregivers.

Some subjects did not report conferring with others about their perceptions at this stage. The cognitive shift of acknowledging that something was wrong with the ADR for these subjects appeared to be strictly a private, internal process.

b) Family Caregiver Interactions With Non-Family

There appeared to be little significant change in the quantity of interaction that family caregivers had with non-family. Family caregivers did not rely on non-family for reinforcement of their suspicions about ADRs' behaviors during this stage. When subjects looked back to this period of time they reported that non-family behaved in ways that suggested that they, too, suspected that something was wrong with the ADR. However, there was little or no communication between family caregivers and non-family about the ADRs' behaviors at this time.

Discussion

Data related to this time period illustrated a process of family caregivers becoming aware that something was wrong with the ADR. The subject said to herself that "something is not right" with the ADR. The ADR was identified as the source of 'trouble'.

Some subjects indicated that this process was internal and other subjects talked about conferring with other family members to justify their perceptions about the ADR. Rose (1983) described family reactions to mental illness within the family as being a family matter or a private matter. Some subjects did not turn to others to talk about what was happening in their relationship with the ADR. They perceived the difficulties they were having with the ADR as a private matter during this stage. Keeping the perceptions within the family or to one's self may have been the result of the family caregiver's feelings of uncertainty about the source of the 'trouble' caused by the subtleness of the initial behavioral manifestations of Alzheimer's disease, the vascillation between 'normal' and 'abnormal' behaviors and family caregiver self-blame regarding the cause of the 'trouble' in the relationship with the ADR.

Some subjects did receive confirmation of their suspicions from other family members, which appeared to move them quickly into Stage II of the process of change for family caregivers. However, turning to others for confirmation of the initial perceptions that something was wrong with the ADR was not required in order to achieve the new insights related to the cognitive shift of Stage I. The process of emerging recognition was completed when the subject acknowledged to herself that something was wrong with the ADR.

Propositions Generated from the Data

Propositions which were generated from the data related to Stage I were:

1) The more knowledge family caregivers had about Alzheimer's disease prior to Stage I, the more quickly they will identify that something is wrong with the ADR.
2) The more confirmation a family caregiver receives from other family members about her observations of the ADR in Stage I, the faster she will acknowledge that something is wrong with the ADR.
3) The more intimate the relationship between the family caregiver and the ADR prior to an initial awareness that something might be wrong, the greater the amount of relationship conflict during Stage I.

B. Stage II: Making My Own Decisions

The second stage in the process of change began with the family caregiver's awareness that something was wrong with the ADR. The major theme of the interactions during this stage focused on the family caregiver's attempts to provide adequate care for the ADR and on finding out exactly what was wrong with the ADR.

Family caregivers' experiences varied considerably during this stage. The most significant difference resulted in the emergence of two distinct groups of family caregivers. Family caregivers who were spouses of ADRs tended to provide care for the ADR in their own homes during this stage, the time span ranging from seven to fifteen years. Primary family caregivers who were adult children of ADRs tended to institutionalize their ADR in a nursing home during this stage. This form of institutionalization usually took place after a variety of family caregiving arrangements had been attempted. The adult children all reported feeling they had no choice regarding their decision to institutionalize the ADR in a nursing home during this stage. These family caregivers felt that adequate care and supervision could not be provided without twenty-four hour supervision from formal caregivers.

Nursing home placement of an ADR was chosen because family caregivers feared for the physical safety of the ADR. In these situations family members felt they had no other alternative but placement in a nursing home because of their inability to provide constant supervision for the ADR. Other reasons given for the decision to place the ADR in a nursing home were career responsibilities, her "own family" responsibilities, and lack of physical space for the ADR to be housed with her. Several subjects stated that had it been financially possible for the ADR to be adequately supervised and cared for outside an institution, that would have been a preferred method of caregiving during this stage.

> . . . nobody was prepared to look after her. You know, we all had to work. And kids were all in school. And none of us had kids old enough to look after him. So there was really no alternative but to - we - if we

> could have afforded to have a nurse come in and look after him, would have been the way to do it. But we couldn't have afforded that. So the only other place was the home.

Despite the emergence of these two distinct groups of family caregivers, the data indicated that both groups of family caregivers felt they maintained control over decisions regarding care for the ADR during this stage. Generally spouse caregivers managed care and provided physical and emotional care to the ADR. They made decisions about the quantity and quality of interaction which the ADR had with other family members and non-family. All family caregivers who did not place the ADR in a nursing home provided physical and emotional care to the ADR without formal assistance until the last three to four months of this stage.

Though participants felt there were no alternatives regarding the decision to institutionalize the ADR in a nursing home, child family caregivers were solely responsible for the decision to place the ADR in the institution and had control of making the arrangements for admission to the nursing home.

> [the psychiatrist] recommended at the time - he said, "I would definitely place him as soon as I can." And I said, "Well, I can't do that. I'm going to make an effort to see what we can do at home." And as I say, that lasted maybe a little longer than a year until when my mother died. Then I realized . . . it was around that time that I had him reassessed because I thought things were - you know. I thought he needed supervision and I was a bit afraid because I wasn't home. And I didn't know what he was going to do and I didn't know whether or not I could really trust him, you know. And then I had Meals for Wheels bringing in meals. And I had to explain that to him. And the meals would be left there in the evening and he'd forget to eat them, or he didn't want to eat them, or -

> so I said, "Gees! I've got to do something," you know. "I really do." Because, I mean, you know, he's going to do something. So that's when he was reassessed again.

They made decisions about whether to search for alternative living arrangements, which nursing home to choose for the ADR, and their own level of committment to care provision and/or management during this stage. These family caregivers handed over the twenty-four hour supervision and physical care to nursing home staff, but their actions indicated that they remained actively involved in and maintained a high degree of control over the management of care. They continued to maintain major decision-making control over the care management. For example, one subject hired a companion for the ADR while he resided in the nursing home. This helped the family caregiver deal with her concerns about the quantity and quality of formal care the ADR was receiving in the nursing home. It was one way to maintain control over the management of care. Another family caregiver described how she removed her ADR from the nursing home when she felt that care and supervision were no longer adequate. Most subjects talked about their frequent visits to the ADR residing in the nursing home. During these visits they provided physical care and emotional support to the ADR and expressed concerns to the nursing home staff about the quality of care. These were other methods of maintaining control over care management.

Most of the ADRs were diagnosed by physicians as having either Alzheimer's disease or senile dementia of the Alzheimer's type (SDAT) during this stage. Those participants whose relative was diagnosed initially with SDAT and were later diagnosed with Alzheimer's disease, spoke of these labels as though they were two distinct conditions. Two ADRs were initially diagnosed as having a psychiatric disorder, such as manic depression and chronic depression.

Participants were confused about the diagnosis and this had considerable impact on the family caregivers when the initial diagnosis was not Alzheimer's disease. Some family caregivers, though unclear about the meaning of the diagnostic labels, felt they knew all along that the ADR suffered from Alzheimer's disease, regardless of other medical diagnoses. These subjects had some previous knowledge or experience with Alzheimer's disease prior to Stage I.

The cognitive shift of this stage occurred when the family caregiver acknowledged to herself that she needed more help with the provision and/or management of care of the ADR. Participants who cared for ADRs outside institutions came to this awareness after long periods of time where they attempted to deal with care provision and management on their own or with minimal help from family members. A series of situational events and the progressive deterioration of the ADR led these subjects to their shift in thinking. Family caregivers felt they had exhausted themselves and all their options. They felt that they had "no other choice" but to hand the care of the ADR over to a formal system of care. The time frame of this stage varied for these subjects and ranged from seven to fifteen years.

Family caregivers who institutionalized the ADR in a nursing home also experienced the new insight that more help was needed. These participants appeared to come to this awareness on two occasions during this stage. They experienced the realization that more help was needed prior to taking action toward institutionalizing the ADR in a nursing home. They also appeared to experience a similar cognitive shift after the ADR had been cared for in the nursing home for time periods ranging from one and half to three years. This second cognitive shift moved these family caregivers on to Stage III.

Data related to the second cognitive shift provided evidence that family caregivers and/or formal caregivers of ADRs institutionalized in nursing homes took responsibility for the decision to seek help when provision of care for the deteriorating ADR in the nursing home was no longer suitable. This awareness occurred after several events related to wandering and aggressive outbursts directed at nursing home staff and other nursing home residents.

> . . . one of the problems was that his wasn't a locked nursing home. Because it didn't have to be . . . Because it wasn't locked and a kind of supervised place, he would see whether or not somebody was at the desk and then . . . you know, make a beeline for the door whenever no one was around. And, ah . . . they couldn't really supervise him all that well and I realized he needs a supervised location because he's going to get himself killed. . . . I didn't really want to see him go that way and end being run over or causing an accident or being found somewhere, you know. And I said - that's the time I pursued it even more fully. And I talked to the staff over at the [nursing home]. They did another assessment and they - well in fact they suggested to me that they could really no longer look after him. Because they thought he was no longer - he was more of a problem. At that point he was getting worse and they suggested at the time that I contact [the psychiatric institution], which is what I did.
>
> . . . they weren't equipped to handle him anyway. He was getting to the point where he was a screamer, and ah . . . they just don't have the staff to handle that type of situation . . . He got to the point where language was abusive . . . screaming and kicking his heels, and never happy about anything really . . .

The family and formal caregivers concurrently "reached a critical point" where the care the ADR was receiving was no longer perceived as being satisfactory for the needs of the ADR. In most situations the formal caregivers from the nursing home assisted the family caregiver in taking action to get more help for the ADR. Family caregivers found themselves in conflict with formal caregivers from the nursing home in some situations, one despite acknowledgement by formal and family caregivers that more help was needed to provide adequate supervision and care for the ADRs.

The cognitive shift for all family caregivers was the result of a series of events rather than a singular event. Phrases such as, "I said I got to do something," "I knew that it was coming," "something will have to happen," and "I could see it coming" illustrated that the shift in thinking was not precipitated by a singular event, but through some build-up of events which family caregivers experienced over a period of time. In situations where the ADR was being cared for outside an institution, the subjects told of events which occurred in the hours and days preceeding the ADRs' admission to a health care facility. Family caregivers talked about the ADR keeping them awake at night, and this seemed to be the single identifiable precipitating factor to getting some action. They also talked about having sleepless nights prior to the awareness that more help was needed. In one situation the spouse was physically ill and contacted the community nurse for some assistance. The community nurse then arranged for the ADR to be admitted to an acute care hospital. The ADR was later transferred to the psychiatric institution from the acute care hospital. Another subject who was caring for the ADR at home took him to a hospital emergency in the early hours of the morning where he was admitted. He was subsequently admitted to the psychiatric institution from the acute care hospital.

In situations where the ADR resided in a nursing home there also appeared to be no single event resulting in the cognitive shift of acknowledging that more help was needed.

a) Family Caregiver Interactions With Family Members

i) Relationship With The ADR. The ADRs became increasingly dependent on the subjects for assistance in meeting their basic physical needs and activities of daily living during this stage. The stage lasted several years for most participants and they chose specific interactive events with the ADR which demonstrated a pattern of increased dependency.

> We'd reached a point where I couldn't get out the door . . . And he was so dependent on me that I didn't dare move, but when he was right at my side.

With the increased dependency of the ADR, primary family caregivers took on expanded roles of increased management of household and/or personal affairs of the ADR. Family caregivers provided physical and emotional care to ADRs. They also took over management of financial concerns and activities of daily living such as becoming the sole car driver, taking responsibility for household and yard maintenance, and becoming the ADRs' social connection to the outside world. These roles were not necessarily new roles for caregivers, but they did involve greater activity or committment by the caregivers as compared to the previous stage. These changes in roles reflected the changes which occurred in the relationship between the family caregiver and the ADR over the years. Description of the interactions between the ADR and the family caregiver illustrated these role changes.

Family caregivers also experienced a continuation of their previous family roles such as spouse or daughter. Interactions within these positional roles were dependent on the behaviors of the ADR which vascillated between usual and unusual behaviors, which is characteristic of the disease. Early in this stage the vascillation in ADR behaviors were less dramatic. However, as the years passed the vascillation in behaviors gradually evolved to a point where behaviors varied from minute to minute with no identifiable pattern to the changes. At this point few interaction patterns from prior to Stage I were identified.

One other expanded role for subjects during this stage was that of visitor to ADRs who were institutionalized in a nursing home. Only adult child primary caregivers placed the ADR in a nursing home during this stage. Child family caregivers reflected on visiting experiences with the ADR prior to Stage II, but none of these included discussion of visiting the ADR in an institutional setting. After institutionalization of the ADR in a nursing home the family caregiver took on the role of the ADR's advocate in communications with the institution's formal caregivers.

ii) Relationships With Other Family Members. Primary family caregivers' experiences illustrated feelings of isolation from other family members during this stage, though they did talk about interactive episodes with other family members. They felt isolated in their roles as major providers and/or managers of care for the ADR. Most of the family help that was provided to primary family caregivers involved daughters and sisters and a son in one situation where there were no other family members available. However, the primary family caregivers did not feel they received enough practical and/or emotional support from other family members.

> I guess actually you feel that maybe everybody should be helping you more so it's not such a load on you. I know my counsellor made me realize too. She says, "Well, why does it have to be you that all this is put on?" She says, "You should be getting help from each family member. And" - but each family member seems to have problems.

Two themes related to the property of isolation consistently arose in the data. One major theme was that of primary family caregiver protection of other family members. Participants reported primary caregiving interactions which were intended to protect the ADRs, and the children, grandchildren and/or nieces and nephews of the ADRs. Protection was achieved through isolation of ADRs from family members for the purpose of preventing emotional turmoil of the ADR and other family members. This isolation of the ADR was accompanied by isolation of the primary caregiver from other family members.

Another theme in the data was the pattern of balance between closeness and distance in family interactions. Family members provided help to the primary family caregiver with care of the ADR during crisis situations by giving advice and by providing practical assistance with daily living. Spouse caregivers received help in dealing with extreme paranoid behaviors and in supervision of the ADR and housekeeping from family members during a postoperative convalescence. In these situations there was no report of family interaction or receipt of assistance with caregiving on a regular basis. In other situations adult child caregivers co-ordinated their visits with the ADR in the nursing home or in his own home for the purpose of relieving the caregiving burdens of the primary child caregiver. The participants who reported these situations also talked about receiving ongoing emotional support from a sibling with whom they had regular interactions. In one situation a brother provided emotional and practical support to the female primary family caregiver. This brother and sister described their relationship as having "always been very close." Another brother provided support to the primary family caregiver with care management decisions during a crisis situation. This data suggested that these adult child primary caregivers received more emotional and practical support from family members than the spouse primary family caregivers.

The issue of distance in family interaction patterns was suggested by the absence of discussion of help from family members during non-crisis periods and through illustrations of intentional distancing from the ADRs. For example, one son of an ADR was involved in caregiving and eventually took over the role of primary caregiver with the illness and death of the spouse caregiver. He discussed his emotional need to continue to distance himself from "the situation" and from the ADR. Another son of an ADR consciously distanced himself from the situation to avoid "interfering" with the primary caregiver's management of the care of the ADR. A third male child caregiver described how provision of practical care to the ADR created conflict within his own nuclear family.

> Well, you see, my (ADR) never did live with me because my wife couldn't handle it. I could - he come and stayed with us and I devote all my time to him, or most of it. My wife got to the point where she says, "Well, either your (ADR) goes or I go." You know . . . So it was only right to treat her fairly.

Female family members also distanced themselves from the ADR and the primary family caregiver. The reasons given for this distancing were based on the female family members' inability to emotionally cope with the deterioration of the ADR.

> She could have did [sic] much more to take the load off but she didn't . . . She had a breakdown herself. She just doesn't have the patience for it. She's involved with having family problems at her place and it's too much for her.

b) Family Caregiver Interactions With Non-Family

Family caregivers had increased interaction about the behaviors and needs of the ADR with non-family during this stage. Relationships with non-family were discussed in terms of interactions with nursing home staff, physicians, and community service providers, all considered part of the formal network of caregivers. The informal network included neighbors and friends. This definition of formal and informal networks was consistent with that of Zarit et al. (1985) in their discussion of social support.

i) The Formal Network. Though participants had increased contact with formal caregivers during this stage, they maintained control over the number of visits with formal caregivers, the type of formal helping services utilized, and decision-making regarding the care of the ADR.

All family caregivers had increased frequency of interaction with general practitioners about the condition of the ADR. The participants did not feel that these physicians were able to provide the ADR with the help which the family caregivers felt was needed. Primary family caregivers also suggested that the general practitioners were unable to help direct them with care provision for the ADR at home. Five participants described having to go to extreme lengths before receiving the medical attention they felt was required.

> And I kept insisting to the doctor that-that he should be taken to the [Geriatric health care facility] and tested there and have an assessment done. And he just kept telling me, "Oh, leave him alone. He's happy. He's happy. Leave him alone. You keep phoning me and telling me to try something which I did all the time." And he was mad at me for doing that. So we went to another doctor-my own physician and he helped me. We switched doctors and this doctor agreed that he should be assessed.

The physicians' roles were described in terms of prescribing medication for ADRs and caregivers, diagnosing the ADRs, encouraging nursing home placement and making referrals to other physicians (specialists such as internists, psychiatrists and neurologists). All ADRs were diagnosed by a physician as having either senile dementia of the Alzheimer's type (SDAT) or Alzheimer's disease at varying points during this stage. Only one subject reported feeling relieved at the diagnosis of Alzheimer's disease in her ADR. This occurred after a lengthy process which included misdiagnosis of a psychiatric illness and treatment for other unrelated physical ailments.

Those subjects whose ADR was initially diagnosed with SDAT and later diagnosed with Alzheimer's disease spoke of these diagnostic labels as though they were two distinct conditions. This suggested a lack of knowledge about these medical diagnostic labels. The diagnoses seemed to be irrelevant information in these family situations. Most of the family caregivers were focusing their mental and physical energies on provision and management of care for the ADR during this stage. A diagnostic label for the condition of the ADR did not appear to provide them with relief from the energy being expended. Thus, the diagnostic label was generally perceived as language used by formal caregivers to label what the family caregivers were attempting to deal with, and the importance of this diagnostic process varied with each subject.

Community nurses visited all ADRs who were cared for at home during this stage. This type of community service did not appear to be instituted until the last three to four months of this stage. This finding was remarkable considering that the stage lasted from five to fifteen years for the family caregivers. The participants perceived the role of the nurses as being to "check in" on how the ADR was doing and to provide the caregiver with emotional support, care supervision and aid with ADR bathing. Participants did not feel that the community formal caregivers were able to assess the condition of the ADR adequately because of the changes in the ADRs' behaviors among strangers.

> And the thing is that the [ADR] does not present what they are to a - someone coming in - the way they really behave in their own family situation. The minute a stranger comes in they're different people.

Other community services for aid with home care were only mentioned by a few subjects. For example, one family caregiver had arranged Meals on Wheels to deliver a daily meal for a short period of time for the ADR who was essentially unsupervised during the day.

The community care services were instituted by formal helpers in situations where the primary caregivers were spouses. They were also initiated by a few child primary family caregivers. The spouse caregivers turned to family physicians and appeared to have the perception that it was the physician's responsibility to arrange or advise the family caregiver of the appropriate community aids to caregiving.

Adult child caregivers' interactions with formal caregivers in nursing homes were discussed at length during this stage. In the period immediately after the ADR was placed in the nursing home, family caregivers focused on their feelings about the decision to institutionalize the ADR and the difficulties the ADR had in adjusting to the nursing home environment. Most of these participants did not discuss their perceptions of the quality of care in the nursing home until after the ADR had resided there for a period of time. After the condition of the ADR had deteriorated all the participants perceived the formal caregivers of the nursing home as being unable to adequately care for the ADR. Family caregivers talked about their concerns regarding understaffing in the nursing homes, inadequate supervision of those with wandering behaviors and lack of compassion demonstrated by nursing home staff toward the residents.

ii) The Informal Network. The informal networks of family caregivers included relationships with neighbors and friends. Only one subject relied on a neighbor for assistance with activities for daily living (i.e., grocery shopping). Other subjects talked about how the ADRs bothered the neighbors with their confused and disoriented behaviors.

All family caregivers reported having minimal contact with friends during this stage, and there was no report of friends visiting the ADR or family caregiver in their own homes or in the nursing home. For example, one friend provided assistance for the ADR on one occasion when she happened upon him having difficulty in a grocery store. Another family caregiver reported that a friend gave her some good advice at one point during this stage. Again, considering the length of Stage II, this finding was extraordinary. Other subjects talked about occasionally socializing or working with friends, but they did not report turning to friends for emotional support or for assistance with the provision of care. The subjects who were asked about informal support from friends in general indicated that they were not surprised that friends avoided providing emotional or physical support. Family caregivers did not consider these as roles of friends. Friends were not expected to help with family caregiving.

> I don't think anybody's friends would want to be a part of it . . . I really don't. I wouldn't say to . . . a good friend . . . "Well, come on let's go out and visit Mother." Because it wouldn't be fair to him . . . They won't phone you up and say, "Well, gee. I don't want to see you going out there by yourself. I'll come with you."

> . . . They shy away. They don't want to really hear about it, you know. "Gee, that's too bad." That's all they say . . . I wouldn't even think of asking one of my friends to do that. I don't - you know, - I'm not angry at friends for not going out and seeing because I understand. I don't think I would want to.

This finding was significant because it was not supported by the literature. Zaret et al. (1985) stated that family caregivers "are more likely to turn to relatives or friends for assistance than social agencies" (p. 109). The participants in this study did not appear to turn to friends for support with caregiving.

Discussion

The major theme in this stage was the process of family caregivers making their own decisions about the care of the ADR. This theme eventually became the title for the stage. The length of time for this stage varied with each subject, but it ranged from five to fifteen years. Individual differences in the length of this stage may have depended on personality characteristics of the family caregiver (i.e., individual levels of tolerance, individual levels of patience in caregiving, etc.), ADR behaviors and the availability of other family members and non-family to assist with care.

All primary family caregivers were female except in one situation where there was no female family member available. Where primary family caregivers were spouses of the ADRs, family support came from children of the ADR and same generation relatives of the primary family caregiver. When the primary caregivers of the ADR were adult children, family support came from their siblings. Primary family caregivers were most often supported by female family members, though male family members also offered support. Adult child primary caregivers appeared to receive more emotional support from family members than spouse caregivers.

All family caregivers experienced some role change during this stage. These changes were suggested through descriptions of interactive episodes with family members and non-family. The role changes were reflective of deterioration of the ADR and created varying amounts of strain for family caregivers.

All subjects suggested a pattern of increased social isolation during this stage. There were variations in degrees of isolation depending on where the ADR resided and which family member was the primary caregiver. All primary family caregivers spent time interacting with others for the purposes of protecting the ADR and other family members from some of the avoidable emotional turmoils associated with experiencing a loved one suffering from Alzheimer's disease. This isolation of the ADR from others also isolated the primary family caregiver from other family members and friends who could have provided emotional support.

Family caregivers had increased frequency of contact with formal caregivers during this stage. The process of family caregiving became more public than in the previous stage. All family caregivers described not giving up caregiving duties until they felt there was no other alternative. This supported the literature which proposed that families do not abandon their elderly family members.

Support resources for family caregivers which were discussed in the literature included: informal family and community supports, self-help groups, formal support groups, day/respite care and institutional care (Barnes et al., 1981; Fisk, 1983; Gross-Andrew & Zimmer, 1978; LaBarge, 1981; Luke, 1982; Montgomery, 1984; Robertson & Reisner, 1982; Scott et al., 1986; Thompson & Doll, 1982). Robertson and Reisner (1982) reported that the Canadian community resources available for family are considerably underdeveloped. There was minimal discussion in the literature about family caregiver experiences with respite care and community home care.

Though there was increased contact with formal caregivers, family caregivers generally appeared dissatisfied with the help they received or did not receive from the formal caregivers. In a majority of the families initial contact with non-family regarding concerns about the ADR were reported as interactions with family physicians. The subjects who did not report initially seeking assistance from a general practitioner provided and managed care of the ADR until much later in the stage, at which time they sought out a physician who specialized in either psychiatry or psychogeriatrics. Folstein (1984) and Cohen (1984) discussed the role that general practitioners and psychiatrists play in the treatment of Alzheimer's disease and suggested that management of the diseased individual was of major importance for these formal caregivers. Physician support for family caregivers was not perceived in the medical literature as a major role of physicians.

Spouse primary caregivers tended to provide and manage care in their own homes without much family or formal assistance until the last three to four months of the stage. Adult child primary caregivers tended to institutionalize the ADR during this stage after various attempts to provide care in some other way. Considering the omission of discussion of nursing home care immediately after the ADRs' admission and the focus of discussion on the inadequacy of the nursing home environment after the ADRs' condition had deteriorated, it appeared that nursing homes were able to provide adequate care for the ADRs until their contdition deteriorated. Literature supported the data which illustrated some of the dilemmas faced by adult child caregivers who had to deal with the responsibilities of care for elderly patients, while being expected to provide care and supervision to their own children (Archbold, 1983; Shanas, 1979; Stone et al., 1987; Treas, 1977).

Events precipitating the cognitive shift which moved the family caregiver onto Stage III appeared to be benign in comparison to other distressing experiences which family caregivers reported experiencing with the ADR. Caregivers who provided care to ADRs at home during this stage reached a critical point where they could no longer continue to provide care for the ADR without more help. These caregivers contacted formal caregivers (i.e., a community nurse, a physician and emergency staff in a general hospital) in most situations. An exception was a case where contact with formal caregivers was initiated by a community nurse. At this point twenty-four hour care for the ADR was turned over to formal caregivers.

Family caregivers whose ADR was institutionalized in a nursing home during this stage experienced the cognitive shift of this stage more than once before moving on to Stage III. The cognitive shift occurred prior to placement of the ADR in a nursing home and then again prior to the psychiatric institutionalization related to Stage III. In a situation where the cognitive shift occurred a third time, the shift occurred prior to institutionalization in a nursing home, prior to removal of the ADR from the nursing home by one of several primary family caregivers, and again after provision of care for the ADR at home for a short period of time prior to psychiatric institutionalization.

Propositions Generated From The Data

Propositions which generated from the data related to Stage II were:

1) Female family members are more likely than male family members to become primary family caregivers.
2) Spouse primary caregivers are more likely to provide care to the ADR outside an institution than adult child primary caregivers.
3) Adult child primary caregivers are more likely to institutionalize the ADR in a nursing home during Stage II than spouse caregivers.
4) The longer a family caregiver provides for an ADR outside an institution, the more likely she is to utilize formal caregiving community services.
5) Primary family caregivers who care for the ADR at home have more control over provision of care than primary family caregivers who have an ADR residing in a nursing home.
6) The longer the primary family caregiver provides care for the ADR at home, the longer the primary family caregiver maintains control over care for the ADR.
7) The more prior experience a family caregiver has with Alzheimer's disease, the less meaningful the medical diagnosis of the ADR is for the family caregiver.
8) The more protective the primary family caregiver is of the ADR, the more socially isolated the primary family caregiver feels during Stage II.
9) Adult child primary caregivers are more likely to receive emotional support from other family members than spouse caregivers.
10) Female family members are more likely to provide emotional support to primary family caregivers than male family members.

11) Interactions with friends and neighbors are more likely to focus on socialization than on emotional support regarding the family caregiving experience.

C. Stage III: Accepting Decisions Of Others

This third stage in the process of change in the family caregiving experience began with the cognitive shift of Stage II where the caregiver acknowledged that more help was needed in order to provide adequate care for the ADR. This cognitive shift resulted in family and/or formal caregiver actions which moved the ADR toward psychiatric institutionalization. Three types of situations were found in the data related to Stage III. Primary family caregivers who cared for the ADR at home responded to ADR behaviors in ways which resulted in the ADR being cared for in an acute care hospital. Most ADRs who had been institutionalized in a nursing home during Stage II remained in the nursing home until their admission to the psychiatric institution. In two situations the ADR was cared for in the home prior to psychiatric institutionalization.

Primary family caregivers who had provided care for ADRs at home were usually relieved of the role of providing twenty-four hour care and supervision. This role was taken over by formal caregivers from an acute care hospital during this stage. This turning over of the physical care to formal caregivers placed these primary family caregivers in a position where they had to become more compliant to formal caregivers' decisions regarding care for the ADR.

Adult child caregivers who placed the ADR in a nursing home experienced a similar position of having to comply with decisions of formal caregivers during Stage II. However, during that stage they appeared to maintain control over major care management decisions.

For example, when physical care provided by formal caregivers in the nursing home was not of a quality which was acceptable, the family caregivers took action in attempts to make adjustments to the quality of care.

> He went back and lived there in the lodge . . . and then they would find him leaning up against the wall sleeping. They'd find him laying on the floor sleeping. He was bumping into things and hurting himself and not knowing he was hurt . . . They didn't have a clue because they didn't have time to keep an eye on him . . . So I went and got him. Took him to the hospital and the arm was broke. And when I went to take him back to the lodge they didn't want me to bring him back there.
>
> And I hired a woman because it was getting to the point that he just wasn't getting the care he needed. And I thought well . . . rather than me, you know, being uptight about it, I'm just going to hire somebody.

These types of interventions were not mentioned by family caregivers during Stage III. Perhaps the participants' increased compliance with the advice of the formal caregivers during this stage was influenced by acknowledgement of the ADRs' deterioration to a point where more formal help was needed.

All family caregivers were generally more willing to accept the physical care provided by formal caregivers during this stage as compared to Stage II. They were also more willing to accept the decisions of formal caregivers, such as the decision regarding placement of the ADR in a psychiatric institution. In the previous stage family caregivers were consistently reluctant to accept advice or treatment plans of formal caregivers in each family situation. The title for Stage III emerged from this change in family caregivers' thought.

The cognitive shift of Stage III was the acknowledgement that the decision to admit the ADR to the psychiatric institution was appropriate for the ADR. The subjects had a variety of responses to the news that the ADR was to be admitted to a psychiatric institution for care and treatment. All subjects gave illustrations of their initial shock or non-acceptance of this treatment plan, followed by descriptions of how they resolved their inner conflicts regarding the psychiatric institutionalization.

> So it surprised me quite a bit you know. I said, "Oh, my doctor didn't talk about . . . [the psychiatric institution]". Well, I said, "If he's got to go he's got to go." That's all. It was - I couldn't say he's not going.

> Well, I was kind of reluctantly pushed into it . . . because I think that they (the nursing home staff) felt they had their hands full. And they couldn't possibly spend the time with him. And I could see the way he was and the worries I had.

There appeared to be no distinct time differences between the ADR admissions to a psychiatric institution from nursing homes as opposed to those from acute care facilities. Time between the initiation of action and the actual admission to the psychiatric institution ranged from one to four months.

In those families where ADRs were admitted to the psychiatric institution from the family caregivers' homes, the time from the cognitive shift of Stage II to admission to the psychiatric institution was considerably less than in the other family situations. Formal caregivers considered the admission of the ADR to the psychiatric institution as an emergency and admission took place within one week after the cognitive shift of Stage II. The aggressive and/or wandering behaviors of the ADRs were no longer manageable at home by family caregivers and the conditions of the ADRs were considered too severe for a nursing home environment.

a) Family Caregiver Interactions With Family Members

i) Relationship With The ADR. During this stage family caregivers had little meaningful verbal interaction with the ADR because of the ADR's mental deterioration. However, all family caregivers described their continued attempts to provide some physical care for the ADR. ADRs who were institutionalized in an acute care hospital or in a nursing home prior to psychiatric institutionalization received care and care management from family caregivers who visited with the ADR frequently. In this stage there was an increased number of participants who were no longer primary physical care providers. This role was taken over by formal caregivers. However, family caregivers remained actively involved in management of the ADR's physical care.

> When he first came into the [acute care hospital] the nurse asked me, "Does he take off his teeth to go to bed?" I said, "No. He just wash them and put them in his mouth and he sleep all night." She said, "Well, we'll have to take it off because we are afraid that he might get choked." Well, I said, "If he get choked it's not because of that. It make over 40 years that he wears false teeth and he never take them off."
>
> It was weeks . . . and I noticed that he never had meals and I didn't realize that in that ward you had to pick your meals just like you do everywhere in the hospital . . . And we asked . . . and they said, "Well, your father never picks his menus." And I mean they could see his glasses were like the bottom of Coke bottles . . . And I asked them what day they send menus down. So from that day one of us was always there for sure in the morning or every afternoon to do the menus . . . I knew what kind of food he liked.

Family caregivers whose ADR was at home provided most of the physical care for the ADR during this stage until the time of the ADR's admission to the psychiatric institution. In the situation where the primary family caregiver removed the ADR from a nursing home and attempted to care for him at home, the family caregiver experienced an increase in direct physical care for the ADR.

ii) Relationships With Other Family Members. This appeared to be a stage where there was increased communication between family members. Interactions between family members focused on the primary family caregiver's actions and the decision to admit the ADR to a psychiatric institution.

In one situation the primary family caregiver attempted to stop the process of the ADR's admission to the psychiatric institution and involved other family members, with whom she normally had minimal contact, to help stop the process. In other situations primary family caregivers defended their actions and beliefs to other family members who were perceived to be disapproving.

> She said I wouldn't have brought him to the hospital. I said . . . "We have to think about us too you know. You know, when it's just too much . . . you can't wait to the last."

Thus, family interactions were found to be supportive in some situations and not supportive in others. Family members were frequently supportive through expressions of interest in what was happening in the family situation. They were not necessarily supportive in terms of being agreeable to the primary family caregiver's decisions regarding management of care. Whether family members were supportive or non-supportive to primary family caregivers, there appeared to be an increase in the frequency of interaction between family members during this stage.

b) Family Caregiver Interactions With Non-Family

Subjects only discussed their interactions with non-family members who were formal caregivers during this stage; there was no mention of friendships. The three types of formal caregivers mentioned in description of interactions were nursing home staff, acute care hospital staff and staff who worked in the psychiatric institution. In all situations the decision to admit the ADR to a psychiatric institution was made by formal helpers, and the family members described being informed of the decision after it had been made. In a situation where the subject initiated contact with formal caregivers at the psychiatric institution, she described feeling "reluctantly pushed into it." Even when this subject was involved in the decision-making process, she did not feel that choices were available to her.

Participants who had interactions with formal caregivers from the nursing home felt that those formal caregivers could no longer care for the ADR adequately because of uncontrollable aggressive and/or wandering behaviors of the ADRs. Formal caregivers of the nursing home were reported to have made the decision that the ADR would be or should be transferred to a psychiatric institution in most situations. Family caregivers were informed of the decision after it had been made by the formal caregivers. Family caregivers felt no alternative but to accept the decisions of the formal caregivers in these situations. For example, one subject eventually agreed to consent to the transfer after being informed that the ADR could be transferred to the psychiatric institution without the family caregiver's consent. In another situation the nursing home staff did not make the decision to transfer the ADR to a psychiatric institution. They did, however, make the decision that they could no longer take the responsibility for care of the ADR. They informed the primary family caregiver of this decision, at which time she quit her job, removed the ADR from the nursing home and unsuccessfully attempted to care for the ADR at home until his psychiatric institutionalization a short time later.

Participants who interacted with formal helpers in acute care hospitals during this stage also described how the formal caregivers informed the family members of the decision to transfer the ADR to a psychiatric institution. Prior to being informed of the decision primary family caregivers expected the ADR to be admitted to a nursing home or auxillary care facility, or sent home. They did not expect that their actions would lead to psychiatric institutionalization of the ADR and they felt that they had no alternative but to accept the formal helpers' decisions.

The participants whose ADR was in an acute care hospital were also dealing with the adjustment to the institutionalization of the ADR during this stage. Their interactions with institutional staff about the ADR indicated concerns about the quality of care the ADR received. For example, one spouse who had cared for the ADR at home expressed dissatisfaction about the care in terms of his personal hygiene. Another family caregiver talked about having to monitor the ADR's nutritional intake to ensure that he received appropriate quantities of food that he liked. These concerns were similar to some of those expressed by family caregivers whose ADR was placed in a nursing home during Stage II.

Some partipants spoke of their perceptions that the ADR was not "bad enough" to be admitted to a psychiatric institution. This may have resulted in some resistance from the family caregivers to the decision to transfer the ADR to a psychiatric institution.

Perceptions of the institution depended on family caregivers' previous experiences with mental illness or psychiatric institutions.

Participants who had no previous experience or negative experiences attempted to deal with their perceptions of the "nut house" during this stage.

> Our memories of that place were very very bad. I promised my father years ago that I would never see him in that place over my dead body. And I wasn't going to admit him. But [the doctor] and my brother's wife told me I had no choice . . . He assured me of the facilities they had out there now was completely different from 25 years ago when he was in there. And they would take me for a tour . . . make me more relaxed about where he was going to be. Because at that time I thought of the nut house. Just crazy people out there and they would hurt each other or the nurses would be treating the patients mean, like they did 25 years ago . . . The nurse talked with me and took me in another room . . . I felt better after they talked to me about it . . . and they gave me a complete tour of all the different wards for the Alzheimer's patients . . . I was really impressed. I was relieved that my father was finally getting help.

Most subjects who described their previous experience with the psychiatric institution or mental illness with indifference either did not discuss their preconceptions of the institution or indicated that they did not have negative feelings about mental illness or the institution. Several subjects spoke about their interactions with the staff from the psychiatric institution during tours of the institution which were offered to family caregivers. Most family caregivers were more willing to accept the formal caregivers' decision to admit the ADR to the psychiatric institution after they toured the facility and spoke with the institution's caregivers. It appeared that exposure to the psychiatric institution helped dispell some of the family caregivers' myths about the psychiatric institution. They experienced a process of redefining psychiatric institutions, similar to the subjects in Rose's (1983) study.

Interactions with others on the day of the ADR's admission to the psychiatric institution were significant for some subjects and were not mentioned by others. Those subjects who accompanied the ADR to the psychiatric institution talked about the event in terms of personal emotional strain and strain of the ADR.

> It was the hardest moment . . . A point where I had to turn around and leave him. But that was the moment that was the hardest. Back to the car and came home . . . I knew I had to face the apartment by myself.
>
> And the doctor that admitted Dad was asking Dad these questions . . . and she (my sister) took him aside and really told him that she didn't like the fact that . . . he was asking [her] these questions as if my father wasn't there.

Discussion

A change in perceptions of psychiatric institutions and a new awareness of the severity of the ADR's illness allowed the family caregiver to acknowledge the need for the ADR's admission to a psychiatric institution and to move onto the next stage of adjusting to the psychiatric institution. Increased family interaction about the ADR and the decision regarding psychiatric institutionalization suggested that this was a crisis period for family caregivers. All subjects reported that the decision to admit the ADR to the psychiatric institution was a decision made by formal caregivers. All subjects co-operated with the formal caregivers even when they felt uneasy or disagreed with the action being taken. They felt they had no other alternative but to go along with the formal caregivers' decisions. Participants were more compliant with advice of formal caregivers regarding care of the ADR in this stage as compared to previous stages.

Psychiatric institutionalization of the ADR required emotional adjustments of family members regarding the meaning of mental illness and the symbolism of psychiatric institutions. Several participants did not feel their ADR was "bad" enough to be admitted to the psychiatric institution, which implied dramatic perceptions of mental illness. Most participants who had no experience or negative experiences with psychiatric institutions described some change in thought during this stage about psychiatric institutions which allowed them to move on to Stage IV.

Propositions Generated From The Data

Propositions related to Stage III which were generated from the data were:

1) The greater the number of negative past experiences with mental illness or psychiatric institutions, the more the family caregiver will resist the decision regarding psychiatric institutionalization of the ADR.
2) The more psychiatric institutionalization is perceived by family caregivers to be a crisis, the greater the frequency of family interaction during Stage III.
3) The longer the provision of physical care to the ADR at home, the greater the adjustment required by the primary family caregiver to having the ADR institutionalized.
4) Formal cregivers are more likely to make the decisions regarding psychiatric institutionalization than family caregivers.

D. Stage IV: Adjusting To The Psychiatric Institution

The fourth stage in the process of change for family caregivers began after the cognitive shift of acknowledging the formal caregiver's decision to admit the ADR to a psychiatric institution. This cognitive shift moved the family caregiver onto the process of adjusting to the environment of the psychiatric institution.

Most participants were interviewed during this stage in the process of change. These family caregivers were interviewed between one and twenty-four months after the ADRs were admitted to the psychiatric institution. The participant whose ADR had died prior to her participation in the study experienced her ADR residing in the psychiatric institution for approximately three years prior to the ADR's death. Thus, data were collected from participants who were at different phases in the process of acknowledging the loss of the ADR in Stage IV.

Some participants denied the severity of the ADRs' illness, as they had done in previous stages. These subjects participated in the study within six months after the ADR was admitted to the psychiatric institution. Other participants whose ADR had resided in the psychiatric institution for six months or longer suggested having begun to accept the loss of the ADR by talking about having made plans or arrangements for the ADR's death when it occurred (i.e., agreement to autopsy, partial payment for funeral expenses, etc.). One family caregiver reported feeling that the ADR as she "had known him" was "already gone" even though the ADR's physical death had not yet occurred. This type of sentiment was talked about by most participants. All participants indicated during this stage that they knew the ADR would never get any better and that further deterioration was imminent. However, the family caregiver's continued ability to hope that the ADR would improve despite his progressive deterioration during this stage was outstanding. This was portrayed by all participants through repeated interpretations of the ADR's behaviors as being appropriate for a given situation or as being normal considering the ADR's personality traits.

> They tried to get him into program activities and things like that . . . and he wasn't interested. He'd say he was and then when they'd want to go somewhere, he didn't want to go. He was never really a joiner to begin with, so it may have been difficult for him to ever get into things like that.
>
> The minute he looks at you, he says, "Take me home. These people are all crazy." Well (laugh), you know, he's sitting there and you're thinking, why are you here Dad?
>
> I said, "I'm C. Who are you?" . . . Then after a few seconds we all heard, "I am myself." And I had been just sitting there . . . and boy did I straighten up and listen . . . I thought, you know, what is this? Is there something happening? Is there clearing? But I - I then realized.

This pervasive feeling of hope was underlying in discussions of issues related to the cause of the disease, ADR relationships with other family members and in family caregiver and ADR relationships with formal caregivers. The feelings of hope seemed to exist even while the family caregivers were acknowledging the loss of the ADR as the person they once knew.

> But you always wish that they'll get cured and they'll come back home, you know. That's the ideal we got.
>
> You never lose that. The slightest thing could make me wonder if there was a change.

During the interviews most of the subjects asked the researcher for information about the cause of Alzheimer's disease. Family caregivers were trying to understand and make sense of the disease in terms of how it might relate to their own future. All participants focused on genetic causes of the disease, though some participants discussed whether an "active mind" would prevent the disease.

> But you often wonder too with Alzheimer's if it - if you keep your mind active when you're younger and - and use it all the time. But they haven't ever done a study on that have they to really feel - like they don't really have any idea what causes it do they?

A few participants wondered aloud whether the disease had developed from long term substance abuse. Family caregivers also showed their concern about genetic causal theories of Alzheimer's disease, early in the interview process when the family tree was being constructed, by assuring the researcher that their children were adopted.

Participants who expressed most interest in the cause of the disease were adult children of ADRs. These participants focused on the genetic causal theories of the disease. This implied that they had fears about developing the disease themselves in the future. Some participants were very serious in their discussions about the cause of the disease and others used humor.

> . . . I'm afraid . . . because both my parents were the way they were, maybe that might happen to me and I might end up in a situation like that. And I find it very difficult to identify with that kind of thing.
>
> If any of us could see what the future holds, would any of us be here?

Though there were situational variations, all family caregivers went through a process of learning the rules of the psychiatric institution. They also had to learn what their own roles were and about the roles of formal caregivers.

Spouse caregivers also talked about their adjustments in lifestyle and feelings of loneliness during this stage.

> . . . I find it hard because . . . I'm always alone . . . Sometimes I work and I try changing my mind, but sometimes I drop tears thinking about him.
>
> . . . because I am alone . . . it's a change. Nobody to look after, I mean, you know, to worry after . . . you're by yourself. That's it . . . it kept me occupied when he was here, very much so, to watch him and see what he was doing and . . . so, when there is none of that, well, it's a change. You're alone, you know.

The cognitive shift of this stage occurred when the family caregiver acknowledged to herself the loss of the ADR as the loved one that he once was.

> At first when he went to the hospital I missed him a lot . . . You always think that they are always going to come back - back home, you know. But now when we start to really realize that for the rest of his life there - I don't know, it gets us . . . upset, and it gets us . . . that he gonna pass the rest of his life with strangers . . . We start to realize that that's a long life.

a) Family Caregiver Interactions With Family Members

i) Relationship With The ADR. During this stage subjects were not able to verbally communicate in any meaningful way with the ADR. Some participants referred to the ADRs' behaviors as being "child-like" and that they had to have all their basic physical needs met by others. Family caregivers had varying amounts of contact with their ADR, though it appeared that contact with the ADR decreased considerably as Stage IV progressed. Participants perceived their roles in the relationship with the ADR during this stage as being a visitor, an observer, a caregiver, a protector and a family member.

Primary family caregivers continued to try to be involved in some way in the provision of physical and emotional care when they visited the ADR. Many family caregivers talked about their interactions with the ADR in terms of "helping out" the staff with the ADRs' care.

> We used to go there and help the nurse, you know, make him eat once in awhile. To give a chance to the nurse, you know.

Adult child caregivers appeared to discuss issues related to the emotional care of the ADR to a greater extent than issues concerning specific physical needs of the ADR during this stage.

> I get depressed too, and there's times I'm close to tears, but I don't let [my ADR] see it. Because I think it wouldn't be good for him . . .

Participants also talked about interactions which illustrated their continued efforts to manage the ADR's care while he resided in the psychiatric institution. Management of care during this stage included observing for changes in ADRs' behaviors and/or physical condition and speaking to formal caregivers on behalf of the ADR when there were concerns about the provision of care.

Visiting the ADR in the psychiatric institution was an adjustment for all subjects. It appeared that as the ADR resided at the institution for longer periods of time visiting frequency decreased. Difficulties with visiting were discussed in terms of distance of the facility from the family caregiver's home, transportation difficulties and the emotional strains associated with visits with the ADR in the psychiatric institution. Discussions of the emotional strains suggested feelings of helplessness resulting from seeing the ADR and other residents of the psychiatric institution in increasingly vegetative states.

> This is hard . . . I know he gets the care there but . . . it's hard to accept. Of course, you see him when he was well and now he's not so. This . . . this part is very hard, but . . . you have to cope with that.
>
> . . . I guess I use - sometimes use the work as a crutch for not going. Because I find it really difficult to go there. I really, really find it difficult . . . When you see people who have been ah . . . electricians or carpenters, or world musicians or whatever . . . sitting in a baby chair and playing with their mouths . . . I don't know how I would cope with it . . . my reaction to some of that is kind of to pull away . . . because I'm really, really frightened off by it, you know.

Some participants talked about feeling guilty about having to institutionalize the ADR in the psychiatric institution. Most of these participants were adult child caregivers.

> . . . it's hard. It makes you think, well, maybe I should have done more for him, maybe he wouldn't have been like that.
>
> I think my father's mad at me for putting him in there - putting him anywhere other than looking after him myself. Which I would have done gladly had I been able to do that. But I could not bring him here and have him wander out onto the street or into the back alley and fall down the steps or lord knows what he could have done to himself here. But I really think he's mad at me . . . I don't know if that's guilt . . . But I really think that because I'm the oldest and I'm in

> charge, I think down deep if it's the last thing that he ever does remember it will probably be that I put him there.
>
> I still feel guilty . . . I feel like maybe it would have worked out if I would have kept him at home.

Participants also reflected on their roles as family members by "looking back" at how things used to be in the family prior to Stage I. These reflections included descriptions of ADRs' previous personality characteristics and previous interactions with the ADRs during conflict and crisis situations.

> I think he's always been a very aggressive person. Like I even think back when we first got married, I mean he had his ways of getting his own way . . . Even as a young boy at home, he did. You know that's been his nature right from - being aggressive you know.

ii) Relationships With Other Family Members. All participants referred to situations where they provided emotional support to other family members who had difficulty visiting the ADR during this stage.

> She thinks it's horrible . . . She says, "I pray to God I never have to come to a place like this. And she gets very depressed . . . And I told her, I said, "Try not to cry." You know, like I get depressed too . . . If you want to cry do it after . . . It's unsettling for [her] and I told her, I said, "Well, don't come too often. Why upset yourself?" 'Cause then she goes home and stews about it. And you know that isn't a positive thing for her.

Some participants talked about their dependency on other family members for help with transportation to visit the ADR in the psychiatric institution. Most participants relied on other family members for "company" when they visited the ADR. This data showed that family caregivers continued to have contact with other family members. However, it appeared that the intensity of family interactions associated with Stage III subsided during this stage to a pattern similar to that of Stage II and earlier. Family members appeared to interact with primary family caregivers more frequently during crisis situations. Once the ADR had been admitted to the psychiatric institution, frequency of family interaction decreased to the non-crisis frequency of interaction. For example, one female child primary caregiver indicated that she had not spoken to her brother since the ADR had been admitted to the psychiatric institution. She described having frequent interactions with him during Stage III of the family caregiving process of change. Other subjects talked about involving family members in conferences with formal caregivers during Stage III and there was no discussion of such family conferences associated with Stage IV.

b) Family Caregiver Interactions With Non-Family

Family caregivers talked about experiences with and perceptions of formal networks and informal networks during this stage.

i) The Formal Network. All interactions which family caregivers had with the ADR during this stage involved interaction with formal caregivers in the psychiatric institution. Participants felt the care which the ADR received in the psychiatric institution was adequate or better than what they had previously received or could be receiving at home.

> I'm content about him being there. Because I know he's getting the best possible care. I may not agree with some things they're doing there, but he's better there than what he was

> living in here and at the lodge. He's better than when I was taking care of him.

Participants described the nursing staff in the psychiatric institution as being "nice," "co-operative" and "kind." However, these participants also indicated that the nursing staff did not always do things that family caregivers expected them to do.

> But if they don't put them (the ADR's dentures) on, he won't wear them no more, you know. I guess they figure he's better off without them, but they should have them in for me.
>
> . . . got his hair combed and he's clean and stuff, I feel very good about it. And then when I see him . . . with blood around his mouth and stuff, well I can't see any reason for that . . . I've been there late in the afternoon and he's still got his lunch on his face. I don't see any reason for that. I feel that - no you can wipe a baby's face in about one minute.

Participants talked about formal caregivers who provided basic physical care to the ADR, but there was a continual sense that participants felt this was not enough. Though all subjects empathized with the enormity of the job of caring for individuals suffering from Alzheimer's disease, they continued to report experiences which were disturbing to them in terms of the quality of care their ADRs received.

Family caregiver dissatisfaction related to issues concerning ADRs' clothes, basic physical care of the ADR (i.e., degree of cleanliness) and the inconsistency in the personalized care which the ADR received (i.e., having his hair combed and dressed up nicely versus an unkept appearance).

> . . . the clothes are the big problem . . . When I ride there and I see that he gets somebody else's clothes it . . . it just burns me. Because now what I got for my [ADR], that the only pleasure we got now to wear his own clothes and what other pleasures he got? . . . I told them. I told them very politely. I said, "I'm buying his clothes and I like him to wear his own clothes. Nobody else's clothes.

The situations which concerned the family caregivers did not appear to be consistently occurring events. The significance of single disturbing events may have clouded the participants' perceptions of the experience with the psychiatric institution or they consistently used only one example to describe their experience. For example, some family caregivers experienced seeing the ADR's clothes on another resident when they visited. One described being upset for only a moment, explaining that she could understand how such a mix-up could have occurred. Another participant stated she was very upset and angry that this incident occurred. The incident appeared to have more of an impact on this participant's perception of the quality of care at the institution. The impact of the disturbing events on the family caregivers may have been affected by the length of time the ADR resided at the psychiatric institution. Family caregivers whose ADR resided in the psychiatric institution for longer periods of time seemed to be more ready to defend the actions of formal caregivers by reporting positive experiences they had with formal caregivers on other occasions. This illustrated a process of coming to terms with the depersonalized aspects of institutional care. It was a process of understanding the system and its rules.

> . . . when he went I thought he wasn't treated well . . . He didn't have his clothes. He had the other one's rags on.

> And ohhhh, you know, . . . but finally I understand how it's going and they've got more than one patient . . . And how do they work? They work pretty hard to take care of those patients. So, it's not bad . . .

Many participants had more difficulty accepting the depersonalized aspects of the psychiatric institution. The depersonalized environment of the psychiatric institution was a major theme in the data. Items which symbolized the identity of the ADR for the family caregiver were not given the importance in the institution which family caregivers would have desired.

> . . . the room is barren. I don't know how to describe it . . . it's like a nothing room. The only way you can differentiate - I'm sure [the ADR] can see that he has his pillow on his bed that he knows it's his . . . And I'm sure that's the only thing that he knows that's personal in that room.

> . . . it's so depersonalized. You know it's like you're mental . . . everything is under lock and key, you know. Like I couldn't even go if I wanted to put cream on his face. I have to get staff to open his closet . . . If you want to change their clothes or if you want to wash their face or put cream on them or whatever, that you should be able to do it without chasing around that whole floor looking for somebody to unlock the door . . . I can see why they have to lock it . . . This other man . . . has taken his shoes - his slippers. I'm sure if he could have gone into a closet there would have been nothing left in those closets. So, I just, you know, looked at the whole situation and I'm taking nothing out there. There's no point to it - at all.

Most participants talked about a wish or desire for the ADR to be cared for either in a nursing home or auxiliary hospital, or at home. Several stated that had they been financially able to do so, they would have preferred to have the ADR cared for in their own homes.

> . . . ideally it would be wonderful if everybody had lots of money that they could keep them at home and have a place set up for somebody to look after them on a twenty-four hour basis. But with the way our world is today . . . not many people can do that.

Another major area of difficulty for family caregivers concerned communication with formal caregivers. Almost all participants talked about experiencing some communication difficulties with formal caregivers at the psychiatric institution. The difficulties related to getting information from formal caregivers about the ADR, a general negative attitude or manner which some formal caregivers had in communicating with family caregivers and others, and/or a lack of contact with formal caregivers at the institution. Several participants talked about having difficulty getting information about the ADR from the nursing staff. They learned through interactions with the nursing staff that family caregivers were to get information about the ADR from a physician. This appeared to be one of the rules of the psychiatric institution. General duty nursing staff were not perceived as being responsible for providing support and/or information to family members.

> We are afraid to ask them too much questions because I know the nurses are not supposed to . . . the doctor's supposed to talk first.
>
> You know, you don't sit and converse like you're visiting them [the nursing staff], so you don't really get to know them. You know, I talk to all of them. 'Hello' and 'How are you today,' and this type of thing, but, you know, you can't sit with and converse with them.

Other family caregivers described their discomfort and inability to get information from the nursing staff about the ADR over the telephone.

> I found it awfully hard to phone the hospital. And that long long wait when they were looking after someone that came to the phone. And I hated that. I thought, what a thing to do just to ask a simple question about someone.
>
> I phone at night . . . after they've put them to bed. And - but they don't tell me much. "Oh, he's about the same." . . . It depends if the nurse - sometime we get to talk a little bit. Sometime, well, if they're busy they can't - can't talk. But some they like to talk a little bit, you know.

Family caregivers also talked about a lack of contact with the formal caregivers who were perceived as being able to provide them with support and information about the ADR. This lack of contact with formal caregivers either resulted from participants' repeated failed attempts to contact formal caregives by telephone, the participants' lack of motivation to contact formal caregivers and from the perceptions of which formal caregivers were designated to provided information and support.

> As far as being supportive, we really haven't been out there much to - you know, be around the staff that could really help you. Because most of them are there in the day time.
>
> I'm sure it [formal support] would be there if we went seeking it . . . I'm sure if I wanted to see somebody badly enough, if I went out, I could be seen.
>
> When he left us that day he said, "Phone anytime you want to ask questions." . . . I bet you I've phoned ten times and haven't

> been able to - he's either in a meeting or - you know. And then if he's phoned back I haven't been in and, you know, it's been - And when you're working it's hard to go out when the staff that (you) can talk to is there.

A few family caregivers had attended the formal family support group meetings at the psychiatric institution. These participants stated that the support group had a positive impact on their knowledge about Alzheimer's disease. They also felt that they were "no longer alone" in experiencing a relative suffering from the disease. Participant involvement in the formal support group ranged from attendance at two meetings to active involvement in support to other family caregivers.

Participants who had not attended a formal family support group meeting stated that they did not have the desire or the need to attend such a group. Either the family caregiver did not believe the group would meet her needs for support or she obtained support from other sources such as another family member or a formal caregiver with no affiliation to the psychiatric institution. A participant who had never attended a family support group meeting asked the researcher what took place during the meetings. She had little knowledge about the group, but felt that the support group would not be beneficial for her.

> You just have to cope. So, I don't know, ah . . . if some people need this, ah . . . interaction with other people that their patents are in the same situation. Ah . . . it's not going to make me feel better listening to Joe Doe crying about his family. It's going to make me feel worse . . . that isn't my choice though. That wouldn't give me comfort at all.

ii) The Informal Network. Data related to the property of interactions within the informal network increased in volume from previous stages, though it remained minimal compared to other properties of the stage. Only spouse caregivers talked about social interactions with non-family, though adult child caregivers talked about interactions with employers and other colleagues. A spouse caregiver talked about her interactions with a "best friend" who was shocked at the changes in the ADR since her last visit with him three years previously. Another spouse caregiver talked about her feelings of discomfort when she started to develop male friendships during this stage.

> And on Friday night I go . . . (to the) lions. It's a senior citizen dance. And we have some of our friends there that goes there, you know. So, it's a nice night for me because I enjoy it. The first time I went there, . . . I'd say, "Why couldn't he be here?" You know, at the dance. Because he was a very good dancer and he liked the music. But, I got used to it . . . It's a nice night you know.
>
> He's a bachelor for many years. He's quite - you know, he's an old gentleman. Very nice man . . . And I could hardly - I didn't know how to relate to him when I first went. I hadn't related to men and to - for so long . . . from the time that his illness started. There's a pulling back socially because of all the difficulties you face . . . And there was all of those years that there was no social life . . . After a total of 16 years you don't move out into a social situation that easily . . . At that point I didn't know how to talk to anybody.

These experiences reinforced the property of social isolation experienced by primary caregivers during the previous stages in the caregiving process.

Discussion

It was no longer possible for family caregivers to engage in meaningful conversation with the ADR during this stage. The condition of the ADRs had deteriorated in many cases to a point where the behaviors were described as being "child-like."

Family caregivers described varying amounts of family interaction and support received from other family members, though it appeared that social isolation of the primary family caregivers was maintained or decreased slightly in this fourth stage. The participants suggested that other family members struggled with their own feeling of loss of the ADR during this stage and they tended to turn to the primary family caregivers for emotional support. Few subjects reported receiving emotional support from other family members during this stage.

Family caregivers had less control over care management of the ADR. There was increased frequency of contact with the formal caregivers and family caregivers' visits with the ADR decreased in frequency the longer the ADR resided in the institution. Initially participants attempted to be involved in decision-making regarding daily care management of the ADR in the institution, but this involvement in care management subsided over time. The pattern of decreased family caregiver involvement may have been due in part to the process of adjusting to the loss of the ADR. The distancing from the ADR may have also been influenced by the issues associated with dealing with the social stigma of the psychiatric institution and the depersonalized environment of the institution. Other factors which may have influenced family caregivers in distancing themselves from the ADR appeared to be frustrations at inconsistencies in care of the ADR, obstacles to communicating with formal caregivers, the distance of the family caregiver from the psychiatric institution and the emotional pain involved in watching a loved one deteriorate mentally and physically.

Propositions Generated From The Data

Propositions related to Stage IV which were generated from the data were:

1) The longer the ADR resides in the psychiatric institution, the lower the visiting frequency by the family caregiver.
2) The greater the distance of the psychiatric institution from the residence of the family caregiver, the lower the frequency of visits.
3) The more contact family caregivers have with formal caregivers of the psychiatric institution prior to or at the time of admission of the ADR, the greater the family caregiver's acceptance of the decision to admit the ADR to the psychiatric institution.
4) The more family caregiver observations of the ADR receiving satisfactory care in the psychiatric institution, the more family caregiver satisfaction in having the ADR reside there.
5) The greater the family caregiver satisfaction about communication with formal caregivers in the psychiatric institution, the higher the family caregiver satisfaction with the ADR residing there.
6) The longer the ADR resides in the psychiatric institution, the more able the family caregiver is to acknowledge the psychological loss of the ADR.
7) Adult child caregivers are more concerned than spouse caregivers about the causes of the disease.

8) The longer the ADR resides at the psychiatric institution, the more accepting family caregivers are of the rules and routines of the psychiatric institution.

9) The greater the frequency of family caregiver attendance at family support group meetings, the greater their knowledge about Alzheimer's disease.

10) The more personalized care provided by formal caregivers for ADRs, the greater the family caregiver satisfaction.

11) The greater the frequency of contact family caregivers have with formal caregivers, the less control family caregivers have over care management.

E. Stage V: Moving On

Stage V included data which reflected a process of moving on in the family caregiver's future. Only one participant was able to discuss experiences she had during Stage V. However, participants interviewed during Stage IV talked about their future and about the future of the ADR. They spoke about looking after themselves in terms of daily living, career planning and social activities.

> Very early on I realized I'd have to make my own life. And I don't think it ever left my thinking totally. I knew it was going to be a responsibility. And where would I go and what would I do and what - what turn would I take.

They also talked about the death of the ADR in terms of funeral arrangements and decision-making regarding autopsy of the ADR. The theme of moving on reflected family caregiver interactions which did not focus on the ADR. The interactions illustrated thoughts about the needs and wishes of the family caregiver. The title of the stage emerged from a lengthy interview with a family caregiver whose ADR had died plus the future activities planned by other subjects.

Stage V appeared to begin with the physical death of the ADR. This was a variation in the established pattern of change in the process as previous stages were initiated by cognitive shifts associated with the preceding stage. With the ADR's physical death the family caregiver continued a process of acknowledging the loss of the ADR which began in Stage IV with acknowledgement of the psychological loss of the ADR. The process of acknowledging and accepting the loss of the ADR continued until after the ADR's physical death. The cognitive acknowledgement of the physical death of the ADR was not a "new insight," but rather an extension of the cognitive shift of Stage IV where psychological loss of the ADR was acknowledged. Therefore, no new insights were identified in the interactions of the family caregiver during Stage V. The family caregiver experienced a grieving period which lasted three to four months before she felt that she could move on with her life.

The participant's reflections on past experiences illustrated that the family caregiver continued to have emotional attachments to the ADR. It was important to the family caregiver that the ADR be remembered by family members and non-family as a "vital" and dynamic human being as opposed to an individual who was not emotionally involved with others. This suggested that the family caregiver continued to protect the dignity of the ADR after his death.

The participant described increased frequency and quality of interaction with other family members during this stage. She talked about receiving emotional support from relatives who had not been mentioned during discussion of the previous stages. The relatives supported the family caregiver by providing regular opportunities for her to socialize with other family members and non-family during traditional Christmas activities. This had not been done prior to this stage.

Other family members who had interacted with the primary family caregiver during previous stages also provided emotional support during this stage. In this situation there seemed to be more discussion about the behaviors of the ADR among specific family members. The participant indicated that these family members reflected back to when the ADR was having difficulties during earlier stages, but that they were not able to discuss their observations with the primary caregiver until Stage V.

> He admits now that back in those years my [ADR] was not well and behaving right. Now that it's all over and he fully understands everything he can admit it. But, up until then there wasn't any support real-well, he supported me. That's another story. But, I mean as far as them as a unit - a family unit.

The primary family caregiver had contact with formal caregivers during this stage due to her continued involvement in the family support groups. Sympathy about the death of the ADR was expressed to the subject by the ADR's physician and nurses who had cared for him at the psychiatric institution.

Because of the family caregiver's involvement with family support groups during this stage, some of those formal caregivers from previous stages became friends during this stage. The participant also talked about renewing old friendships from days prior to Stage I in the process of family caregiving and of making new friends through work and social interactions with relatives.

Discussion

Data in Stage V illustrated a process of "moving on" for the single family caregiver who had experienced the stage at the time of participation in the study. The family caregiver experienced a significant increase in social interaction with both family members and non-family. These interactions were emotionally supportive to the primary caregiver regarding her caregiving experience and in relation to building a new life. This finding suggested that other family members and non-family may have felt more comfortable providing emotional support to the family caregiver after the death of the ADR. There are societal prescriptions for responding to and dealing with death and providing support to those who experience the death of a loved one. There are no such societal prescriptions for providing support to primary family caregivers of ADRs.

Because only one subject had experienced the death of her ADR, the significance of the identified properties of this fifth stage in the process of family caregiving was not confirmed. Despite the tentative nature of the findings, the fifth stage was included in the model because a final stage was suggested by all participants. Further research must be done to verify salient concepts related to family caregiver interactions, relationships and roles during this period in the caregiving process.

Propositions Generated From The Data

Propositions which emerged from the data related to Stage V were:

1) Social isolation decreases after the death of the ADR.
2) Interactions with formal caregivers about the caregiving experience decrease suddenly after the death of the ADR.

F. Other Themes Associated With The Family Caregiving Process

The first stage in the family caregiving process had no identifiable beginning and the final stage appeared to have no distinct end. This suggested that the total caregiving experience with a relative who suffered from Alzheimer's disease was connected to the life of the caregiver both before the relative developed the disease and after that relative had died.

The stages of change in the caregiving process were stages which individual family caregivers experienced. Where more than one family caregiver participated in the study, the different family caregivers experienced a similar process, though each family caregiver discussed different experiences and perceptions of the situation. Thus, the process of change for each participant was similar, but within a family any two caregivers could be at different phases of thought development moving toward a particular cognitive shift.

Several themes occurred in the data which were not associated with a particular stage. They either occurred across more than one stage or they were general comments made by several participants. The four common themes of "making sense," "feeling locked out," family obligation and control of caregiving will be discussed.

Throughout the family caregiving process, the subjects attempted to make sense of what was happening to the ADR. They also attempted to make sense of the difficulties they experienced in providing and/or managing care for the ADR. The subjects consistently suggested processes of making sense of situations through discussions about their interpretations of the behaviors of others. In Stage I the behaviors of the ADR were interpreted as being either "normal" or "abnormal" by the family caregiver. Once formal caregivers became involved in managing and/or providing care, family caregivers interpreted and provided rationales for their own behaviors. They also provided rationales for the behaviors of other family members. These interpretations depended on the relationship of the family caregiver to the individual whose behaviors were being interpreted.

Family caregivers talked at length about their interpretations of the ADRs' behaviors. Throughout the five stages in the process of family caregiving the ADRs' behaviors were interpreted as being meaningful. Behaviors which seemed abnormal to the researcher were interpreted by the family caregiver as either being normal personality characteristics of the ADR or as some form of communicated message to the family caregiver.

> Last fall we could talk to Dad . . . I would say to him, "Do you know there's something wrong with you?" And he would say, "Yes." And he'd start crying. Then out of the blue He'd change the subject because he didn't want . . . to face it . . . He's never wanted to face anything in his life really . . . Dad was very weak - very weak that way . . . A very weak person all his life as far back as I can remember.

This suggested denial by some family caregivers regarding the severity of the illness. In the early stages in the caregiving process ADR behaviors were interpreted by some caregivers as a continuation of personality characteristics. In later stages the ADR behaviors were interpreted by family caregivers as not being "bad enough" for admission to the psychiatric institution. After admission to the psychiatric institution all family caregivers described interpreting ADR behaviors in ways which suggested that there might be more to the behaviors than what they appeared to an outsider.

> We as caregivers with this disease cling to anything that slightly resembles normalcy. And we're inclined to interpret some behavior that's sort of like out of the blue and normal, we think to being normal. And we don't realize the impossibility of it. (We're) doing it instinctively.

However, the denial could also be interpreted as feelings of hope for a recovery of the ADR. Participants consistently illustrated throughout the caregiving process a sense of hope that the situation and/or the health of the ADR would start improving. Kubler-Ross (1969) discussed hope in her stages of grief related to death and dying. She defined hope as

> "the feeling that all this must have some meaning, will pay off eventually if they can only endure it for a little while longer . . . that all this is just like a nightmare and not true." (p. 139).

A feeling of hope was evident in all stages of the grief process, as it was in the five stages of the family caregiving process. Kubler-Ross (1969) described feelings of hope as being either a rationalization for the suffering or a denial of the situation in order to 'hang in' during the difficult times.

In attempts to make sense of the situation family caregivers also interpreted formal caregivers' behaviors from Stage II to Stage V. These interpretations suggested that formal caregiving was perceived to be not quite good enough. The levels of satisfaction of formal caregiver performance varied over time and with each subject. However, even those family caregivers who stated that they felt genrally satisfied with the formal care provided to the ADR had complaints about formal caregivers on one or two occasions. The dissatisfaction of formal caregiver behaviors may be similar to the anger which Kubler-Ross (1969) discussed in her second stage of grief. She stated that "anger is displaced in all directions and projected onto the environment at times almost at random" (p. 50). Unlike the grief process, anger directed at formal caregivers in the family caregiving process was evident in several of the stages.

Family caregivers also attempted to make sense of their situation by continually looking back to their interactions with the ADR. Making sense of a specific situation was understood by comparing current interactions to previous interactions and observations. Participants looked back on experiences with the ADR prior to Stage I in all five stages. Thus, the ADR behaviors prior to Stage I where participants experienced a process of realizing something was wrong, were the reference points for participants' interpretations. A continual process of making sense of the experience through use of the thought process described above reinforced the ongoing sense of emotional upheaval experienced during the family caregiving process.

A second major theme or pattern of interaction for family caregivers related to social isolation. In Stage I primary family caregivers did not give any suggestion of social isolation. Their social isolation increased considerably as Stage II progressed. Some participants described an increase in family interaction during Stage III. However, frequency of family interaction appeared to decrease again with the start of Stage IV. Frequency of social interaction with non-family slightly increased during Stage IV for some subjects. There was a dramatic decrease in social isolation for the single family caregiver in Stage V. Not only were primary caregivers socially isolated in terms of family and friends, but they felt isolated from formal caregivers particularly after the ADR was institutionalized. Primary family caregivers also talked about feelings of isolation from the ADR throughout the caregiving process. This isolation seemed particularly difficult for spouse caregivers. Some family caregivers suggested that the environment of the psychiatric institution enhanced their feelings of isolation. These discussions included issues such as the locking of doors and cupboards which contained the ADR's personal toiletries, the inability to maintain items which symbolized the personality of the ADR, communication difficulties with the formal caregivers and the constraints of the formal care system on active involvement of family caregivers in the ADR's care management. The theme of this data illustrated feelings of being locked out, both emotionally and physically.

A third theme in the interviews was that of family obligation. This property of the caregiving process could not be associated with any one specific stage. Several subjects responded to questions related to motivation and perseverance in providing care with answers which suggested strong feelings of obligation. These feelings seemed to be related to the quality of the long-standing relationship with the ADR and the role of the ADR in the family. Kubler-Ross (1969) discussed family obligation in the grief process when she talked about feelings of guilt. She stated that if formal caregivers helped family members 'work through' their feelings of guilt about the relationship with the dying person the feelings of obligation toward that person would diminish.

Most participants spoke either directly about or alluded to feelings of guilt. The interpretations of situations and/or rationalizations of family caregivers' thoughts suggested feelings of guilt. These feelings of guilt may have motivated family caregivers to continue with caregiving, though the relationship between the family caregiver and the ADR appeared to be much more complex. Two adult child caregivers talked about providing care because of the care the ADR had provided during the caregivers' childhood.

> I know there were lots of times when I didn't feel like having to do all that, but you have to do it. I'm sure there were lots of times when I was a little girl and my father didn't feel like doing whatever he had to do with me. But, he had to do it.

> He was always a good person. He always helped everybody. He helped everyone of us kids anytime we ever needed help. And you kind of feel, well, he brought me up and took care of me and now it's my turn to take care of him.

Spouse caregivers also implied that they owed their ADR the caregiving.

> He was a real good husband. That's the thing. I can never say the opposite. He was a husband that looked that I had money. He was a husband that always worried that I get sick. And he was a good husband.

These types of statements also reflected the reciprocal nature in the participants' relationships with the ADRs. Each individual within a family occupied roles dependent on a position within the family. Rodgers (1973) indicated that individuals in reciprocal roles can "pressure an individual to behave in a particular way" (p. 57) and that there can be variations between expected and actual resulting behaviors. The physical and mental deterioration of the ADR pressured family caregivers who were in reciprocal role positions (either spouse or adult child) to take the role of caregiver in return for past situations where the ADR assumed a position of caregiver.

The caregiving experience was not perceived as a negative experience by family caregivers, though the subjects who were asked specifically about this stated that it had been a stressful and difficult experience. They could not agree to give a negative label to the experience.

> I don't think it was a negative experience. At least not to me. It was stressful, but it was - it was good. I could do something for my father that he couldn't do for himself

> . . . No, I don't think I would say it was a negative experience. It was hell when it was happening because of all the time we had to spend there with him . . . But I don't think it was negative.

This finding supported Gilhooly's (1984) statement that there was marginal or inconclusive evidence to support an association between caregiving and low morale and poor mental health.

A fourth theme in the data related to control. Family caregivers frequently talked about their experiences in terms of maintaining control over the care provided to the ADR, particularly after formal caregivers took over the twenty-four hour supervision of the ADR. Interactions between family caregivers and formal caregivers illustrated a common pattern which suggested that with increased involvement of formal caregivers as the stages progressed, there were decreased family caregiver feelings of control over management of the ADRs' care.

> I mean after all he still is our father. We should have the most say over (him) than anybody . . . And especially me now with taking over as his legal guardian and taking care of - I mean, his checks all do come in my name now as his trustee and that. And I'm just, you know, upset with the idea that I have as much control as I thought I would have, you know.

Propositions Generated From The Data

Propositions generated from data related to other themes or patterns of interaction during the caregiving process were:

1) The more assistance family caregivers received from formal caregivers with care provision and management of the ADR, the less control family caregivers have over care provision and management.

2) The more primary family caregivers are engaged in caregiving interactions related to the ADR, the more isolated they are from other family members.

3) The longer primary caregivers provide and manage care for an ADR, the more isolated they are from friends.

4) The greater the family caregiver feelings of obligation, the greater the frequency of family caregiver interaction related to the ADR.

V: CONCLUSIONS

Summary of Findings

These data illustrated a process to family caregiving of a relative suffering from Alzheimer's disease, who resided in a psychiatric institution. Sequential stages within that process emerged as data were collected and analyzed. Properties of the stages suggested a decrease in meaningful interaction with family members and an increase in interaction with formal caregivers as the stages progressed. The general pattern of decreased family interaction appeared to be related to feelings of social isolation for primary family caregivers. Participants also suggested experiencing feelings of isolation from formal caregivers throughout the process. As caregiving for the ADR became more public, family caregivers felt decreased amounts of control over the management of care. Changes in interaction patterns appeared to be related to changes in thought. These changes which family caregivers experienced, emerged into five stages in the process of family caregiving. They were: Emerging Recognition, Making My Own Decisions, Accepting Decisions of Others, Adjusting to the Psychiatric Institution and Moving On.

In Stage I the family caregiver realized there was something wrong with the ADR. This stage had no distinct beginning which suggested that the process of caregiving was attached in some way to the caregiver's previous life. Family caregivers described feelings of confusion until they had identified the ADR as the source of 'trouble.' There was increased conflict between the participant and ADR during this stage. Dealing with the ADR was kept within the family and for many caregivers their thoughts about the ADR remained private. The length of ~~this~~ stage varied with each subject, but it seemed to depend on the participants' past experience with Alzheimer's disease and whether or not the family caregivers' perceptions about the ADR were confirmed by other family members. The stage ended with the cognitive shift of acknowledging that something was wrong with the ADR.

In Stage II the family caregiver gradually turned to non-family formal caregivers for verification of what was wrong with the ADR and for assistance with care provision. Frequency of interaction with formal caregivers increased as the stage progressed. Family caregivers remained in control of care management during this stage, but with an increased involvement of formal caregivers, family caregiver control over care management was generally decreased from the previous stage. The length of Stage II ranged from five to fifteen years and ended with the acknowledgement that more help was needed, which resulted in psychiatric institutionalization of the ADR. Primary family caregivers became increasingly socially isolated during this stage. This was partially due to attempts to protect the dignity of the ADR and to protect other family members from the emotional turmoil of dealing with a loved one mentally deteriorating from Alzheimer's disease. Primary family caregivers spent increasing amounts of energy and time at care provision and management during this stage.

Two groups of family caregivers emerged in Stage II. Adult child caregivers tended to place the ADR in a nursing home and spouse caregivers tended to care for the ADR in their own homes with minimal informal and/or formal assistance.

Family caregivers experienced changes in thought related to acceptance of the decisions of others during Stage III. They acknowledged and accepted the decision of formal caregivers to admit the ADR to a psychiatric institution. In all situations the initial decision to admit the ADR to the psychiatric institution was made by formal caregivers. The family caregivers reported being informed of this decision after it was made by formal caregivers. All but one subject felt they had no choice but to accept the formal caregivers' decision. This process illustrated increased perceptions of loss of control over the ADRs' care management.

Participants appeared to have increased frequency of contact with formal caregivers and other family members during Stage III. Family interactions focused on the formal caregivers' decision to admit the ADR to a psychiatric institution.

Stage IV illustrated family caregivers adjustments to the psychiatric institution. All ADRs resided in the psychiatric institution during this stage and every interaction which family caregivers had with the ADR also involved contact with formal caregivers. Thus, there was increased frequency of interaction with formal caregivers. Participants talked about events in ways which suggested feelings of even less control over care management during this stage. Family caregivers talked of having interactions with other family members, but the interactions focused on visiting experiences with the ADR in the psychiatric institution. Family caregivers relied on other family members for assistance with transportation to the psychiatric institution and for emotional support during visits with the ADR. There appeared to be less contact with other family members in comparison to Stage III.

The cognitive shift associated with Stage IV was acknowledgement of the loss of the ADR. The specific loss acknowledged during this stage was the psychological loss or loss of the personality of the ADR. This cognitive shift was continued into Stage V where the family caregiver acknowledged loss of the physical aspects of the ADR after his death.

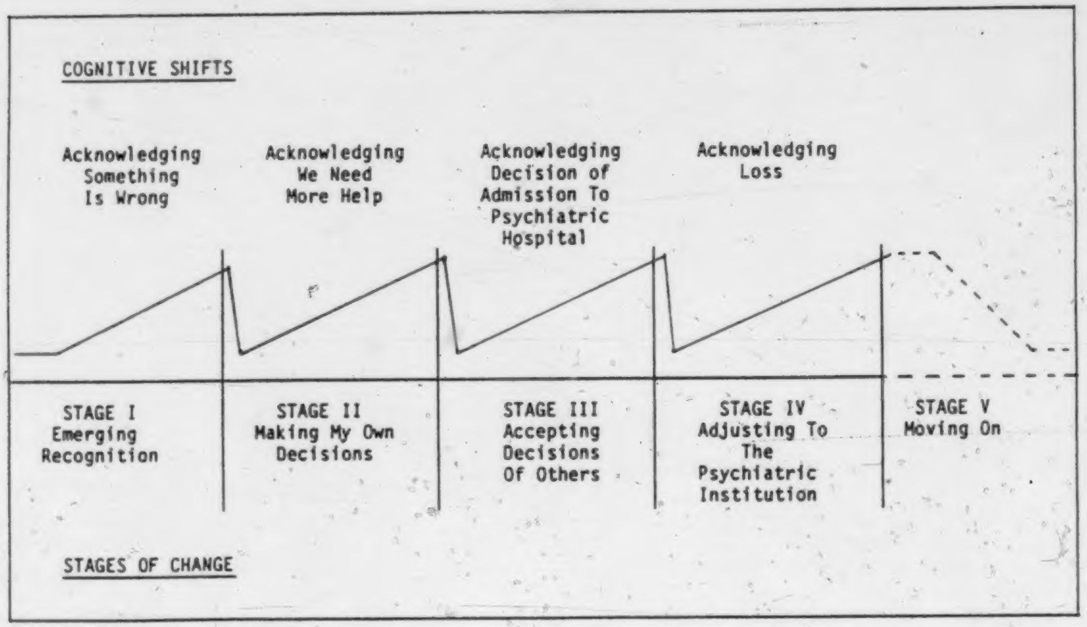
Stage V illustrated family caregiver interactions related to a theme of moving on with her own life. There was increased interaction with other family members which illustrated family support for the grieving caregiver. There was also increased frequency of socialization with non-family. Interactions with formal caregivers regarding the ADR subsided during this stage to a frequency similar to that of Stage I. There was no distinct end to the final stage which suggested that this end of the process was connected in some way to the life of the family caregiver.

A Model of the Process of Family Caregiving

A model of the five stages of change in the process of family caregiving was developed to promote clarity in understanding the phenomenon (Figure 2). The stages were sequential and illustrated the experiences of all participants. The cognitive shifts associated with each stage were also verified by all participants. In two situations where more than one family caregiver participated in the study, data showed that the second and third family caregivers also experienced the five stages of change, with the associated cognitive shifts, in the caregiving process. Data from individual family caregivers were the focus of analysis, but this finding suggested that more than one family caregiver could experience the caregiving process simultaneously.

There were situational and time frame variations with each subject. The degree of each cognitive shift also varied with each subject. Some subjects were more willing to acknowledge a particular shift than others.

FIGURE 2: STAGES OF CHANGE IN THE
FAMILY CAREGIVING PROCESS


COGNITIVE SHIFTS
Acknowledging Something Is Wrong
Acknowledging We Need More Help
Acknowledging Decision of Admission To Psychiatric Hospital
Acknowledging Loss
STAGE I Emerging Recognition
STAGE II Making My Own Decisions
STAGE III Accepting Decisions Of Others
STAGE IV Adjusting To The Psychiatric Institution
STAGE V Moving On
STAGES OF CHANGE

Variations in properties of the stages could occur for caregivers from one family.

Several scholars have utilized stage theory to illustrate the phenomena which they examined, though the rationale for using stage theory and the characteristics of stage theory were not clearly defined. In Erikson's (1963) model of eight psychosocial stages of individual human development distinctions between the stages were based on successful resolution of psychic conflicts which coincided with physical development or physical capabilities, particularly in the earlier stages. Erikson stated that "psychosocial development proceeds by critical steps - 'critical' being a characteristic of turning points, of moments of decision between progress and regression, integration and retardation" (p. 270). Erikson's discussion of stage theory supported the findings presented in this study. The family caregivers of ADRs talked about their experiences and could easily identify the critical steps through descriptions of the most salient events in their caregiving experiences. These critical steps eventually emerged into the five stages of change with the associated cognitive shifts in the process of family caregiving. Each stage of change in the process of family caregiving was a turning point in terms of family caregivers' thought processes and interactions with others.

Rodgers (1973) stated that when studying the family life cycle, units must be created which indicate differences between the units over the passage of time. Units are identified through differences in roles and positions of the actors in each unit and that researchers must arbitrarily choose the differences in characteristics which enhance the comparison between the units. Stages represent "periods . . . which are internally homogenous with respect to some characteristics of importance to the person who developed them and which are also differentiated from each other on these same characteristics" (p. 77). Different categories are developed for different problems, thus the decision to categorize stages in a particular way is operationally based on the research question. Each stage in the process of family caregiving for an ADR represented a different way of thinking for the family caregiver, which resulted in changes in interactions, roles, positions and relationships within the family and with non-family. The choice of categories was based on reflections of family caregivers' experiences and on experiential similarities between subjects.

Both Rodgers and Erikson suggested that stage theories are arbitrarily chosen by researchers to illustrate and clarify thought. Erikson's (1963) model was presented as a "tool to think with" and was not "a prescription to abide by" (p. 270). This also holds true for the process of family caregiving.

Erikson (1963) used 'stage' and 'phase' in his discussion of psychosocial development without clear differentiation between the meaning of the two terms. He appeared to use the terms interchangeably. Rodgers (1973) indicated that 'stage' has been the term typically used by researchers to refer to the units which are comparable. The term 'stage' in the model of family caregiving was chosen to signify a period of time which was considered separately from other time periods in attempts to enhance clarity in the discussion. This process of identifying distinct periods of time was an abstraction.

Glaser (1978) discussed characteristics of the Basic Social Process in terms of a process of change which occurred over time. He indicated that the changes had "discernible breaking points - discernible to the extent that stages can be perceived, so they can be treated as theoretical units in themselves" (p. 98). Stages were described as being sequential and of having a time dimension. The development of data into stages was said to allow "one to follow changes over time yet remain in grasp of a theoretical 'whole' process" (p. 99). Glaser felt the transition from one stage to another was contingent either on some event or a general set of indicators which may be difficult to pinpoint in time. These characteristics of a Basic Social Process were evident in the process of family caregiving.

Significant Theoretical Contributions

Concepts from two existing theoretical frameworks were implicit to the methodology in this study. Chenitz and Swanson (1986) stated that the symbolic interactionist perspective, in combination with the grounded theory approach to research, "provides a way to study human behavior and interaction" (p. 7). They argued that the symbolic interactionist theory was an orientation or perspective which was implicit in the grounded theory approach, rather than it being the framework for operationally defining constructs which were to be further tested.

Symbolic interactionists believe that individuals learn to view themselves and others through their interactions with objects and people. Meaning is attained through interactions with others and an individual's behavior is a reflection of her perception of herself (Charon, 1985; Stryker, 1972). The researcher's understanding of the family member's experience was based on an agreement of the meaning of objects or people and relationships by the researcher and the subject. In order to understand the family members' experiences of their relatives suffering from Alzheimer's disease the researcher had to be able to perceive the experiences from the family members' positions.

In other words, the researcher's goal was to apply the same meaning to the experiences as the family members had. The researcher attempted to take the role of 'other' to understand the meaning of the situation from the emic perspective. To obtain this perspective it was important that the phenomenon be viewed in an appropriate context (Chenitz & Swanson, 1986). The contexts in this study were the family caregivers' homes, the work place in one situation, and the psychiatric institution in another.

Symbolic interactionism is implicit to the grounded theory approach to research. Concepts from developmental theory also guided the method of data collection and analysis in the phenomenon examined in this study. When it appeared that the phenomenon being examined might be a process, data were organized on time lines and compared. Concepts of time and changes over time were implicit to this method of analysis.

Alzheimer's disease is a degenerative neurological disease which progresses gradually over a number of years. Time is a key factor in any examination of the diseased individual and those who care for them. Gwyther and Matteson (1983) discussed the process of the disease in terms of behavioral changes of the individual and the parallel changes and challenges which were faced by family members. As the disease progresses and the ADR changes, family members' interactions, roles, positions, and relationships also change.

Family caregivers' experiences with an ADR were related to time because of the importance time played to the characteristics of the disease. Admission of the relative to a psychiatric institution was the one event which made this sample distinct from other family caregiver samples in the literature. This event occurred at some point during a progression through the family life stages and at some point during the individuals' and family members' progression through the disease process. It was, therefore, assumed that events and experiences for family members were time related, but whether there was a particular sequence of events for the phenomenon was unclear at the outset of the study.

This developmental process orientation to family caregivers' experiences of their relative with Alzheimer's disease suggested an orientation which included concepts from family developmental theory. According to Hill and Rodgers (1964) the focus of developmental theory is on "change in the process of internal family development . . . with the dimension of time being central" (p. 200). The families with a relative suffering from Alzheimer's disease were assumed to have experienced some internal changes or developments over the progression of the disease. This framework did not provide a basis for operationalization of concepts, but rather provided a perspective which directed the process of data collection and data analysis.

In summary, grounded theory experts state that symbolic interactionism, which enhances the study of human behavior, was implicit to their specific method of research. In the examination of the phenomenon of family caregiving of an ADR an additional theory was implicit to the methodology. Developmental theory includes concepts related to time, positions in time and roles, which were important factors in viewing the Basic Social Process of family caregiving experiences related to a relative suffering from Alzheimer's disease. These two theories were implicit to the study's methodology.

Limitations of the Study

A major limitation of the methodology was in the selection of the sample. The listed next-of-kin may not always have been that family member who was most involved in the caregiving or care management.

Use of this theoretical or purposive sampling technique could have biased the analysis. Selection of additional family members as participants in the study depended on the recommendations of the first family participant. Selection of additional family caregivers was based upon their willingness to participate, the co-operation of the listed next-of-kin in providing information about the other family members and on the requirements for data collection and analysis. This selection may have excluded family members who had participated in caregiving prior to the ADR's psychiatric institutionalization. The selection process may also have excluded other family members who held influential positions within the family which were not perceived as such by the listed next-of-kin.

Not all subjects were interviewed individually. In two situations two family caregivers were interviewed together. In both situations both family members participated in caregiving, but one family member was more actively involved in caregiving. It may be argued that the researcher was not able to get accurate information about these caregivers' experiences with a second family member present during the interview. This did not appear to the researcher to be the case in these two situations. Family members agreed with each others' experiences during the interviews, but they also disagreed. The interview process appeared to catalyse discussion between the two family members. These discussions provided the researcher with further insights about the properties related to interactions between family members.

All of those listed next-of-kin who were contacted by telephone by the researcher agreed to participate in the study. Though the subjects were informed that participation in the study would in no way affect the well-being of their ADR, family caregivers may have felt that their participation could have some positive influence on care the ADR received in the psychiatric institution.

Data from adult child caregivers and spouse caregivers were not specifically differentiated at the outset of the study. This may have had considerable affect on the emergence of the stages, particularly in Stage II. However, the purpose of the study was not to differentiate groups of caregivers, but to describe the caregiving exerience from a nonspecific group of family caregivers whose ADR resided in a psychiatric institution. Researchers may wish to further examine differences in the caregiving experiences of these two groups in future studies.

Reliability of the findings related to Stage V was compromised through interviewing only one participant who had experienced the death of the ADR. Though the interview with this family caregiver was extensive and support for these findings was provided by subjects interviewed during Stage IV, the salient properties of Stage V were not confirmed. Interviews with additional subjects who had experienced Stage V would have increased the generalizability and reliability of the findings of that stage.

The findings illustrated the experiences of a specific group of ten family caregivers. These findings are not generalizable to all family caregivers who experience an ADR residing in a psychiatric institution, nor are they generalizable to all family caregivers of ADRs. Generalizability is decreased through the use of the grounded theory approach. Another researcher may have chosen different subjects and analyzed the data in a different way. The findings do, however, provide valuable insights to the experiences of family caregivers which could guide or support further research into this area.

Data were obtained through open-ended interviews done during Stage IV or V in the process of family caregiving. Thus, most of the data were retrospective. Data for Stage IV had less well-defined common themes as compared to earlier stages, perhaps because of the varying lengths of time ADRs resided in the psychiatric institution. Participants were not able to discuss current or recent events with as much clarity as events which had occurred during previous stages. Therefore, data obtained retrospectively was analyzed with greater ease because participants had been able to solidify their experiences.

Implications for Practice

This study may have several implications for family life educators and gerontologists. The findings emerged into a theoretical model of a process of change in family caregiving. Though the findings are not generalizable to the population of family caregivers whose ADR is admitted to a psychiatric institution, nor to family caregivers who do not experience psychiatric institutionalization of the ADR, the model developed through the grounded theory approach provides a new or different way of looking at family caregivers' experiences with an ADR. It also adds to the minimal body of research related to the psychiatric institutionalization of ADRs and to a growing body of literature about family caregivers. The findings may also provide support for family life educators and gerontologists involved in political action related to issues of care for ADRs and family caregivers by focusing attention on the concepts which are salient to family caregivers.

Findings from this study may clarify family caregivers' experiences for formal caregivers. Direction may be obtained from the findings when considering issues related to formal family support groups. Questions of when the support groups are most appropriate for family caregivers and directions of group sessions at various stages of the process may be considered. Formalized follow-up with family caregivers who do not attend support groups might also be investigated. Findings illustrated that contact with formal caregivers from the psychiatric institution on or before the ADRs' admission to the psychiatric institution influenced family caregivers' perceptions of the institution and feelings of satisfaction about formal caregiving in the institution. These findings may provide support for increased contact with family caregivers, particularly at that time.

Physicians of ADRs and family caregivers may find the study useful in increasing awareness of the family caregiving experience. Findings illustrated a need for increased gerontological education for general practitioners. Physicians must become more educated about community resources available for family caregivers so that these services can be utilized by family caregivers at earlier stages in the family caregiving process.

Community and institutional nurses provided care to ADRs and family caregivers. Findings from the research may provide these formal caregivers with further insights to the family caregiving experience. The study may enhance greater understanding of family caregiver behaviors during interaction with formal caregivers. Issues related to communication between family caregivers and formal caregivers need to be addressed. The findings may support continued education in areas of self-awareness and communication skills for formal caregivers.

This study may also have implications for family members of ADRs. The five stage model may help these family members understand the process which they are experiencing. Some family caregivers may be relieved to learn that their experiences are not uncommon to family caregivers of ADRs. The interview process itself may have allowed the participants to come to terms with their roles in the caregiving process.

The propositions generated from the findings of this study may guide further researchers in examination of larger and/or more varied samples of family caregivers. Further examination of the nature of the relationships between the proposed salient concepts must be carried out before definitive conceptual relationships can be identified.

Conclusion

Review of the literature prior to and during data collection and analysis unveiled several assumptions and unresearched issues related to family caregivers' experiences with an ADR who resided in a psychiatric institution. The findings from this study provided support for assumptions 1, 2, 5 and 6. Family members wanted to care for their ADR despite the burdens experienced. Family caregiver motivations for long term caregiving were not clear. This could be an area for further study.

In this study one family member assumed more responsibility in caregiving than other family members. However, in most situations other family members were involved in caregiving to varying degrees. This was the case for both institutionalized and non-institutionalized ADRs. A review of the literature yielded the assumption that only one family member took on major caregiving responsibilities while the ADR was cared for at home.

Formal support groups were reported to be beneficial by those family caregivers who attended. This finding was consistent with the literature. The findings also supported the assumption that psychiatric institutionalization is stressful for family members. It appeared that once definitions and perceptions of the psychiatric institution were adjusted so that their ADR and the psychogeriatric facility were perceived as being separate from the rest of the psychiatric institution, family caregivers were more accepting of the ADR residing there.

Data clearly showed that participants perceived themselves as caregivers both before and after the institutionalization of the ADR. This finding was not supported in the literature. The issue requires further examination to fully understand the perceptual inconsistencies.

Scholars also have suggested that family members made the decision to institutionalize an elderly family member. In this study, this appeared to be the case for nursing home placement. However, the decision regarding psychiatric institutionalization of the ADR was consistently made by formal caregivers.

Scrutiny of the ten family caregivers' experiences with their ADR has provided support for properties which have been assumed to exist. The process has also led to discovery of other properties related to the family caregiving process which have yet to be examined. Further research with larger numbers of subjects needs to be done before the five stage model can be utilized directly in practice with family caregivers and before relationships between concepts and properties put forth in the propositions can be identified.

FOOTNOTES

[1] Male pronouns will be used to refer to ADRs in further discussion.

[2] Female pronouns will be used to refer to family caregivers in further discussion of this study, though it is acknowledged that male family caregivers are primary caregiving in some situations.

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APPENDIX A

UNIVERSITY OF ALBERTA
FACULTY OF HOME ECONOMICS
DEPARTMENT OF FAMILY STUDIES

Informed Consent Form

PROJECT TITLE: A Relative With Alzheimer's Disease in a Psychiatric Institution: Family Members' Experiences
INVESTIGATOR: Jayne Willoughby Phone: 432-5771
SUPERVISOR: Dr. Norah Keating Phone: 432-5771

The purpose of this research project is to increase scholars' and health care workers' understanding of families' experiences when their family member is admitted to a psychiatric institution for the treatment of Alzheimer's disease. Interviews will be conducted at least two times and each interview will last approximately one hour. During these interviews questions will be asked regarding your feelings and perceptions about having a family member admitted to a psychiatric institution for treatment of Alzheimer's disease. The taped interviews will not be shared with hospital staff, but the final report, containing anonymous quotations, will be publicly available at the end of the study.

There may be no direct benefits to the participants of this study, but there may be changes in methods of support provided for families who have a relative admitted to a psychiatric hospital for treatment of Alzheimer's disease following the completion of this study.

THIS IS TO CERTIFY THAT I, ______________________________
(print name)

HEREBY agree to participate as a volunteer in the above named project.

I understand that there will be no health risks to me or my relative who is being treated in Alberta Hospital Edmonton for Alzheimer's disease, resulting from my participation in the research.

I hereby give permission to be interviewed and for these interviews to be tape-recorded. I understand that, at the completion of the research, the tapes will be erased. I understand that the information may be published, but my name will not be associated with the research.

I understand that I am free to refuse to answer any specific questions during the interview without penalty. I also understand that I am free to withdraw my consent and terminate my participation at any time without penalty.

I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

______________________________ ______________________________
Participant Researcher

____
Date

APPENDIX B

INTERVIEW GUIDE I

When was your relative diagnosed as having Alzheimer's disease?

How did your relative's admission to Alberta Hospital come about?

How was the decision made for your relative to be admitted there?

What were your feelings or thoughts about institutions like Alberta Hospital before your relative was admitted there?

What changes have occurred for you and your family since your relative was admitted to Alberta Hospital?

How would you describe your role at the hospital?

How would you describe the roles of the nurses, doctors, and social workers?

What are your feelings about the health care your relative has received?

What things did you find the most helpful/supportive before your relative was institutionalized?

What things have you found to be most helpful/supportive since your relative has been institutionalized?

If you could give other families who will be faced with a similar experience some advice, what would it be?

APPENDIX C

INTERVIEW GUIDE II

Stage I: Not Recognizing Changes (Watching/Passive Surveillance)

Describe your relationship with your relative before you realized that there was something wrong with them.

Did you have any suspicions during this time that there might be something wrong? What were they?

What were your relationships like with other family members? How often did you see/talk to other family members? Who did you see/talk to? What kinds of things did you do/talk about?

Who in the family made decisions about important issues? What did other family members do when decisions were being made?

Did you have contact with friends/neighbors? How often? What was the nature of the contact?

Did you have contact with health care workers? How often? What was the nature of the contact?

Milestone: Realizing Something is Wrong

Can you tell me about the time when you realized that there was something wrong with your relative?

Was this a sudden awareness or did it kind of creep up on you? Over what length of time would you say?

Do you remember doing anything to help yourself figure out what was wrong? What?

Did you have much contact with other family members during this period of time? What was the nature of the contact? Which family members were involved? Did you talk about what you thought was going on with the ADR at that time? Did family members agree?

Did you have any contact with people outside the family during this *time? (i.e., friends, neighbors, doctors, etc.)?* Who did you have contact with? What was the nature of this contact? Did they help you in any way?

Stage II: Verifying What Was Wrong and Making Choices:

What happened after you realized that something was wrong? What did you do?

Re: Nursing Home Placement:

How was the decision made? When was it made? Who was involved in the decision-making?

How did you feel about the nursing home placement?

Hod did you feel about the staff in the nursing home? Who did you have contact with (i.e., nurses, doctors, social workers, etc.)? Were you pleased with the care your relative received? Did you ever get angry with the nursing staff?

In general, how did you feel about the situation after your relative was placed in a nursing home?

How often did you get to see your relative? What kinds of things did you do when you visited?

Who made decisions regarding the care of your relative after s/he moved into the nursing home?

Re: Caregiving at Home:

Was it a conscious decision to care for your relative at home? Whose decision was it?

Who was making decisions about the type of care your relative received? Who was involved in providing care? Did you get any other help? From who? What kind of help did you get? When?

How long did you care for your relative at home?

How did you feel about caring for your relative at home?

Did you have any contact with health care workers during this time (i.e., doctors, community services, etc.)? Frequency of contact? Nature of the contact? Did you feel that they helped you and your relative? In what ways?

* * * * * * * * * * * * * * *

How would you describe your relationship with your relative during this time (i.e., frequency and nature of contact)? Were there role changes? Describe them.

Did you have contact with other family members at this time? Who? Frequency? Nature of the contact? (i.e., What kinds of things did/do you talk about?) Feelings about family member contact (i.e., issue of balancing roles, expectations, etc.)?

Did family members agree about decisions being made during this time period?

Did you have any contact with friends/neighbors during this time? Frequency? What was the nature of the contact?

Milestone: Realized There Was No Other Alternative

Did you reach a point where you/nursing home staff felt that the relative needed more care? How long was it before you reached this point? What happened?

Who made the decision to get more help? Were others involved in the decision-making? Who? How was the decision made? Who first expressed the feeling that more help was needed (i.e., you to someone else or someone else to you)?

How were you feeling about your situation at that time?

What was your relationship with your relative like at this time?

Did you have contact with other family members at this time? Who? What was the nature of the contact? What kinds of things did you talk about? Did family members agree with decisions being made?

Did you have contact with friends/neighbors at this time? Who? What was the nature of this contact?

Did you have contact with health care workers at this time? Who? What was the nature of the contact? Did you feel that they helped you and your relative?

Stage III: Accepting Decisions of Others

How long was it before your relative was admitted to the psychiatric institution?

What happened during this time?

Who was involved in caring for/making decisions regarding the care of your relative? How did you feel about the decisions that were made?

Were other family members involved? How? How often?

Were friends/neighbors involved? How? How often?

Were health care workers involved? In what way? Did you feel that they helped?

What was your relationship like with your relative at this time?

How were you feeling about the situation, in general, at that time?

What were your thoughts/feelings about the psychiatric institution? Had you any previous experience with a psychiatric institution?

Milestone: Admission to The Psychiatric Institution

Tell me about the day of admission. What happened that day?

Who was involved? In what way?

How did you feel about your relative's admission to the psychiatric institution?

What were your first impressions of the psychiatric institution?

Stage IV: Feeling Locked Out

What were things like for you after your relative was admitted to the psychiatric institution? Did your life change in any way? How?

What do you do when you visit your relative? How do you feel when you visit?

Describe your relationship with your relative at this time.

Do other family members visit? What do they do when they visit?

Do friends visit? What do they do when they visit?

Do you have contact with other family members? Who? How often? What is the nature of the contact?

Do you have contact with health care workers? Who? How often? What do you do/talk about? Do you feel that they help you and your relative? How?

Have your perceptions of the psychiatric institution changed since your first exposure to it? In what way? How do you feel about your relative being in the psychiatric institution now?

How do you feel about the care your relative is receiving in the psychiatric institution? Do you feel that the psychiatric institution is the best place for your relative right now?

Do you ever get angry with the hospital staff?

What do you do when you are not visiting your relative?

Stage V: Looking Ahead

What do you predict will happen in the months ahead for your relative?

What do you predict for your own future?

Was there a specific time when you started thinking about the future? Did anything precipitate it? What?

General Questions

What has been the most difficult period of time you have had to deal with? How did you deal with things at that time?

What feelings have you found the most difficult to deal with?

Have you felt that any one thing or person was especially helpful for you over the past years? What/Who? In what way(s)?

APPENDIX D
PSYCHIATRIC INSTITUTION APPROVAL

ALBERTA
HOSPITAL
EDMONTON
Psychiatric Treatment Centre
†An affiliated teaching hospital of the University of Alberta
*Accredited since 1974 by the Canadian Council on Hospital Accreditation

Box 307
Edmonton, Alberta, Canada
T5J 2J7

Courier to: 17480 Fort Road

☎ (403) 973-2361

Our File:

Your File:

July 18, 1986

Ms. Jayne Willoughby
4203 - 122 Street,
Edmonton, Alberta
T6J 1Z3

RE: FAMILY SUPPORT FOR ALZHEIMER PATIENTS

The Research Co-ordination Committee is pleased to inform you that your proposal considered September 22, 1986 been accepted with the your changes.

This data is to be part of your thesis research.

MOTION#: (86-27) Approved September 22, 1986.

If you have any further questions please do not hesitate to contact the writer.

Yours truly,

K.L. Checkley, Ph.D.,
Chairman,
Research Co-ordination Committee.

wc
cc Linda Ambrose
Nursing Research Coordinator.

APPENDIX E
UNIVERSITY OF ALBERTA APPROVAL

FACULTY OF HOME ECONOMICS

APPROVAL

for

PROPOSAL ON HUMAN RESEARCH

This is to certify that Jayne Willoughby

a ~~staff member~~/student in the Department of Family Studies

presented a proposal for a research project entitled

Treatment of Alzheimer's Disease in a Psychiatric Institution: A Family Experience

and that the undersigned Committee are now satisfied that the ethical criteria for human research have been met.

Date September 17, 1986

Eloise Murray

Olive Yonge

Sharon McIrvin Abu-Laban

Signatures

NOTE: The original of this form should be returned to the Dean's Office once the Committee has met.